**University of Alberta**

# South Asian Immigrant Women's Perceptions of Respect within Health Professional–Client Relationships While Journeying through Cancer

by

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A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Faculty of Nursing

Edmonton, Alberta
Spring 2007

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395, rue Wellington
Ottawa ON K1A 0N4
Canada

*Your file Votre référence*
*ISBN: 978-0-494-29746-9*
*Our file Notre référence*
*ISBN: 978-0-494-29746-9*

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# DEDICATION

I dedicate this research to my dear mother who passed on of breast cancer at a tender age of forty-nine and to my dear father who taught me that stubbornness is something to be proud of because it gets you to where you want to go. My dear friend Lola, who passed on of breast cancer at age fifty-eight is also remembered. She showed real courage and determination and is sorely missed on the rainy days. I salute my daughters Sophia and Sonya and my granddaughter, Nyssa, who are the daughters of tomorrow; keep up the laughter and the joy. Finally, to all the daughters who have lost their mothers to any form of cancer, I dedicate this scholarly work to you.

## ABSTRACT

Although respect is discussed as a positive outcome of health professional–client relationships, there is a paucity of research on respect in the context of these relationships within clinical settings. Even less information exists about South Asian immigrant women's experiences of respect with regard to health professionals in clinical settings. In this focused ethnographic study, the author examined South Asian immigrant women's descriptions of their experiences and perceptions of respect within health professional–client relationships at two outpatient follow-up clinics at the provincial cancer agency.

Eleven South Asian immigrant women participated in the study. Four women were interviewed twice. The author collected data via audiotaped, semistructured interviews, participant observations, field notes, and document analysis. Data analysis proceeded simultaneously with the data collection.

Issues such as language, cultural values, and beliefs, along with underlying societal, individual, and institutional factors that coexist with health professionals' ability to create respect, were some of the dimensions that influenced how South Asian immigrant women experienced respect. The characteristics of respect experienced as a part of the interaction with health professionals were the professional's way of being, being acknowledged as a human being, the professional's way of talking with clients when providing information, and attending to the person. Some women believed that health professionals make assumptions that stereotype South Asian immigrant women. Women felt that most health professionals provided respect through the use of professional interpreters and some language-specific printed information for women who did not speak English.

Health professionals' capacity to acknowledge South Asian immigrant women as individuals helped to formulate/construct respect for their individual identities. In light of these findings, questions were generated that helped to raise critical consciousness and to foster an awareness of the nature and importance of respect, including the need to pay close attention to diversity and difference by practicing individualized, person-centred care. The author also recommended future research examining discourses in relation to cancer and how communication and language foster respect or not within health professional–client relationships.

ACKNOWLEDGEMENTS

I would like to extend my gratitude to Drs. Anne Neufeld, Joanne Olson and Denise Spitzer for their guidance and mentoring during this journey. Anne and Joanne, thank you for being patient with my persistence in attaining goals and timelines I had set for myself. Both of you always made time for me in your busy schedules when I would travel from Vancouver to Edmonton and you kept me on the straight and narrow path. Thank you to Denise for providing expertise in the area of immigrant health.

I am indebted to all the women who gave of their time and shared their personal experiences with me along with the respect they showed me by offering me tea and nourishments as I arrived in their homes. Your smiles will always be in my heart. This work would not have been possible without the help of the administrators, physicians, and of course the nurses who dedicated their time with enthusiasm. Thank you to my friends both here and afar, who were an inspiration and provided endless support by listening to me. To Analeis and Barb, thank you for your spiritual support and encouragement through each step. I would like to extend my gratitude to Sharon who shared her home with me and mentored me through the ordeals of this journey. To my sisters Usha, Sarita, and Sunita, this is for all the days we walked to school, because only you will know what we shared. To Sunita and Steve, I say thank you for being the special brother-in-law and sister.

To my man, Jerry, you are the best, thank you for closing this journey with me. Nyssa, my granddaughter has shone light and hope into our lives. God bless each one of you who have shared this journey with me. Thank you for holding my hand, dear God.

# TABLE OF CONTENTS


DEDICATION
ABSTRACT
ACKNOWLEDGEMENTS
TABLE OF CONTENTS

CHAPTER ONE INTRODUCTION 1

Purpose of the Study 5
Research Questions 6
The Researcher's Pathway 6
Summary 8

CHAPTER TWO LITERATURE REVIEW 10

Respect 10
Respect as an Ethical Principle 12
Respect as a Component of Relationships 13
Theoretical Framework 14
Relational Epistemological Theory 14
Assumptions of Relational Epistemological Theory 15
Health Professional–Client Relationships and Respect 16
Health Care in a Culturally Diverse Society 20
Immigrant Women and Canadian Society 23
Immigrant Women and Cancer 25
South Asian Women and Cancer 26
Summary 27

CHAPTER THREE METHODOLOGY 29

Qualitative Research 29
Ethnography 30
Ethnography and Nursing Research 30
Focused Ethnography 31
Feminist Standpoint Perspective 32
Assumptions of Feminist Standpoint Perspective 33
Researcher - Reflexivity 34
Study Procedures 38
The Setting 38
Gaining Access 39
Sampling 41
Selection Criteria 41

Inclusion and Exclusion Criteria 42
Recruitment 42
Data Collection 44
Fieldwork 44
Participant Observation 45
Participant Observation Field Notes 47
Interviews 47
Participant Rapport 48
Interview Process 50
Interview Field Notes 54
Document Retrieval 54
Data Analysis 56
Establishing Scientific Rigor 58
Ethical Considerations 61

CHAPTER FOUR FINDINGS 63

Participant Profile 64
The Context of the Clinical Setting 65
Cancer Care Services in the Province 65
Payment for Cancer Care Services in the Setting 68
Outpatient Follow-up Cancer Treatment Setting 70
The Health Professional's Role in the Clinical Setting 74
Journey of a South Asian Immigrant Woman Going through Cancer Treatment 77
The Personal Context of South Asian Immigrant Women's Experiences and Expectations of Respect 80
Women's Understanding of the Cancer Journey 80
Challenges of Expressing Self in Relationships with Health Professionals 82
Previous Health Care Experiences 86
South Asian Immigrant Women's Perceptions of the Health Professional's Approach in the Clinical Context of the Setting 92
Health Professional's Personal 'Way of Being' 93
Courteous Manner 98
Professional Behaviour 101
Being Acknowledged as a Fellow Human Being 105
Being Greeted 109
Non-Verbal Ways of Bestowing Respect 113
Being Treated Equally 114
Ways of Talking When Providing Information 117
Tone of Voice 122
Attending to the Person 125

South Asian Immigrant Women's Experiences of Respect within Health Professional – Client Relationships in the Clinical Setting 129
The Influence of Women's Heritage on Their Experience of Respect 130
Touch 134
Privacy 136
Compassion 138
Reciprocity 141
Consequences of Respect for South Asian Immigrant Women 142
Women's Perceptions of Factors in the Clinical Setting that Influence Their Experience of Respect 145
Communication and Language 146
Staff Characteristics 149
Interpreters 151
Sharing Experiences 152
Making Assumptions 155
My Perceptions of the Factors that Influence Respect 156
Summary of the Findings 159

CHAPTER FIVE DISCUSSION 161

South Asian Immigrant Women's Perception of Respect 162
Respect from a First Nation's Perspective 163
Respect as an Outcome of Cancer Care with South Asian Immigrant Women 165
South Asian Immigrant Women in Other Health Care Settings 167
Health Care Relations and Immigrant Women with Cancer 173
Health Care Relations with Non-Immigrant Women with Cancer 175
Health Care Relations and Other Population 177
Communication within Health Professional–Client Relationships in the Context of the Clinical Setting 179
Fostering Respect within Health Professional–Client Relationships 185
Limitations and Strengths of the Study 189

CHAPTER SIX SUMMARY AND RECOMMENDATIONS 192

Summary 192
Contributions to Nursing Knowledge and Practice 193
Recommendations for Future Research Directions 195
Concluding Comments 197

References 198

Appendices 215

Appendix A: Request for access to the British Columbia Cancer Agency 216
Appendix B: Information Letter 217
Appendix C: Volunteer Recruitment Poster and A Brief Overview of the Study 219
Appendix D: Patient Informed Consent (English) 220
Appendix E: Participant Observation Field Notes Guide 221
Appendix F: Sample Interview Trigger Questions 222
Appendix G: Interview Field Notes Guide 223
Appendix H: Agencies' Mission and Strategy Plan, Policies, and Guidelines 224
Appendix I: List of Educational Material 225

# CHAPTER ONE

## INTRODUCTION

A demographic shift in Canada within the past two decades has resulted in a substantial increase in immigration from non-European countries (Statistics Canada, 2003). Immigrants represent an increasingly large part of the Canadian population. In 2002, more than 5 million Canadians (about 18% of the population) were born outside of the country, and approximately 250,000 new immigrants are received each year (Statistics Canada, 2003). Furthermore, immigrant women, women refugees, and women of diverse ethnic backgrounds form an increasingly large percentage of the Canadian population. This has resulted in an increasingly heterogeneous populace, and recent trends indicate exponential growth (491,725 in 1981-1990 to 1,066,230 in 1991-2002) from Asia, particularly Southern and Eastern Asian countries, inclusive of the Pacific regions (Statistics Canada, 2003). In fact, 51% of emigrants from Asia and the Pacific regions chose Canada as their place of residence within the last two decades (Statistics Canada, 2003).

The destinations of choice for most immigrants to Canada continue to center on the three major metropolitan centers: Toronto, Ontario; Montreal, Quebec; and Vancouver, British Columbia (BC). However, BC, in comparison to other provinces, has experienced the highest proportion of Asian and South Asian immigrant population growth within the past two decades. In the city of Vancouver, for example, the percentage of foreign-born residents from all countries is approximately 30% (Statistics Canada, 2003).

The resulting population heterogeneity presents challenges to the provision of health care within this increasingly diverse Canadian population. The country needs to address these challenges to provide adequate health care delivery for people living with chronic as

well as life-threatening illnesses, which increasingly are occurring within the context of immigration and settlement experiences (Choudhry, 2001; Hislop et al., 2003; Kirkham, 2003; Spitzer, 2000). Health care provision for immigrant women is further complicated by the intersections of the social context of interpersonal relationships within institutional settings, the institutions' ideological underpinnings and premises, and the women's previous experiences with health and life-threatening illnesses such as cancer (Kirkham, 2003; Lynam, Henderson, et al., 2003).

The overall prevalence of cancer in the Canadian population is approximately 2.4% among men and 2.7% among women (Canadian Cancer Society, 2006). Based on current incidence rates, 38% of women will develop cancer at some point during their lifetime. On average, 1,319 Canadian women were newly diagnosed and 608 women died of cancer every week in 2004 (Canadian Cancer Society, 2005). In BC, an estimated 9,100 Canadian women were diagnosed with cancer and 4,100 female deaths related to all types of cancer occurred in 2005 (Canadian Cancer Society, 2005; British Columbia Cancer Agency [BCCA], 2005).

Regardless of gender, cancer patients, to a greater extent than others, have to confront the idea of death and rapidly become aware of the dangers and influences of the psychological, somatic, and social aspects of the disease (Deeny & McGeehan, 1999; Howell, Fitch, & Deane, 2003; Kleinman, Das, & Lock, 1997; Radley, 1993). For most women, cancer represents a complex disease, not only in its physical manifestations but also in its onset, diagnosis, treatment, and uncertainty (Fitch, Ross, & Franssen, 2001; Kayser, Sormanti, & Strainchamps, 1997; Landmark & Wahl, 2002; Singh, 2002). Although most native-born Canadian women will confront various challenges with cancer, these challenges

are usually heightened for immigrant women, who might be struggling with migration and settlement issues, including the challenges of maintaining lifelong beliefs and practices while learning new ways to establish a stable life in the new country (Bhachu, 1996; Bottorff, Balneaves, Sent, Grewal, & Browne, 2001; Choudhry, 2001; Choudhry, Jandu, et al., 2002; Gupta, Kumar, & Stewart, 2002; Hilton et al., 2001; Hislop et al., 2003). For example, immigrant women must deal with the cancer diagnosis as well as other resettlement issues, such as leaving their extended family behind in their country of origin, or caring for other family members, and adjusting to their life in Canada (Anderson, Blue, Holbrook, & Ng, 1998; Bottorff, Johnson, et al., 1998; Choudhry, 2001; Hislop et al., 2003; Lipson & Meleis, 1985; Lynam et al., 2003; Singh, 2002). Furthermore, findings from Baider and Bengel's (2001) study on cancer and the spouse suggest that there are gender-related differences and disparities between men and women in dealing with health care and cancer conditions. In light of the historical tradition of gender differentiation, with its cultural, economic, social, and political issues that are generally compounded with migration and transition experiences, it is important to address the topic of respect within health professional - client relationships for immigrant women, who might be experiencing less-than-ideal health care.

Besides recognizing multiple factors that influence immigrant and nonimmigrant women's health and illness experiences, researchers have examined interpersonal relations and interactions within the socially located health professional–client relationship in the contexts of the health care setting (Bottorff, Balneaves, et al., 2001; Deeny & McGuigan, 1999; Kirkham, 2003; Moyle, 2003; Singh, 2002; Thorne & Robinson, 1988). Previous research has highlighted the importance of respect within health professional–client

relationships; however, research findings have indicated varied understandings of or forms of respect in health care provision (Drew, 1986; Johansson, Oleni, & Fridlund, 2002; McGee, 1994; Oberle & Tenove, 2000). Findings in these aforementioned studies indicate that attributes of respect, such as, honouring the client's context, respecting the client's autonomy to make decisions, ensuring confidentiality, and providing dignified care will lead to patient satisfaction and respectful care within interpersonal relationships.

Other related research has reported that respectful interpersonal connections lead to connected care where the nurse is present with the patient and that providing attentive care and being with the patient generally increase respect within nurse-patient relationships (Deeny & McGeehan, 1999; Dillon, 1992; Dyck, Lynam, & Anderson, 1995; Kirkham, 2003; Moyle, 2003; Schutlz & Carnevale, 1996). Despite extensive discussions in the literature regarding respect as a fundamental component of providing care in the practice setting (Browne, 1993; Dimond, 1999; Erlen, 1998; McGee, 1994) few studies have critically examined how respect is conveyed within the nurse-client domain of nursing (Browne, 1995, 1997; Browne & Fiske, 2001; Kelly, 1987, 1990), and I found even fewer studies that examined the experience of being respected from the client's perspective within health professional–client relationships in health care settings. Even less is known about how immigrant women experience respect in interactions with health professionals. To date, I have found no studies that explore respect as a component of providing care as part of nursing practice, or that examine respect within health professional–client relationships with immigrant women. Given the evidence that most immigrant women will face challenges that are compounded by migration and transition experiences, and because respect is a fundamental component of care, it is important to explore immigrant women's experiences

of respect within health professional–client relationships as they journey through cancer related treatments and follow-up visits in the clinical setting.

## Purpose of the Study

The purpose of this inquiry was to examine South Asian immigrant women's experiences and perceptions of respect within health professional–client relationships. Women who came to a health care agency outpatient follow-up clinic for cancer-related treatments were the participants in the study. For the purposes of this study, South Asian immigrant women were defined as those women who had immigrated from Fiji Islands, India, Pakistan, or Sri Lanka. This was because the two clinical sites chosen for this study served immigrant women primarily from these countries. My interest lay in uncovering the characteristics of health professional–client relationships that could help or hinder the development of respectful relationships during South Asian immigrant women's illness experiences given the socially constructed context of this interpersonal relationship.

The duality of migration and transition experiences along with cancer renders immigrant women vulnerable as they journey through the illness. To reduce the negative impact of these dual experiences, health professionals need to cultivate relationships that create and sustain respect within health professional–client relationships while providing health care. If it is true that respectful relationships reduce differences between individuals and shape the way in which people engage with each other, then respect might play a major role in promoting health and well-being, along with the individual's attaining and retaining an optimum level of health, regardless of ethnicity or gender (Acton, Irvin, Jensen, Hopkins, & Miller, 1997; Henderson, 1978).

## Research Questions

The overall research questions for the study were

1. What are South Asian immigrant women's experiences and perceptions of respect within health professional–client relationships while journeying through cancer?
2. What are South Asian immigrant women's expectations of respect in their relationships with health professionals at an outpatient follow-up clinic? and
3. What factors help or hinder in establishing a respectful relationship between health professionals and clients during their visits to a clinical outpatient follow–up setting?

## The Researcher's Pathway

This next passage is an illustration of an immigrant woman's journey through migration and transition experiences from young adulthood to her standpoint today as a woman and a nurse-researcher. It is important for you, the reader, to journey through my life experiences before you engage with this text. I believe that we respect the *other* and create understanding and respect each time we share and connect with others' *lived experiences* within a human-to-human relationship (Paterson & Zderad, 1976).

I spent my childhood frolicking in the warm Pacific Ocean and exploring the tropical rainforests of the Fijian Islands. At age 15, I immigrated with my family to a contrasting country of massive landscapes, very diverse climates, polar bears, and seals. We were now in a different culture, one that was more competitive than the one we had left behind. After we moved to Canada, things changed dramatically for the family. When

I reached the naïve age of 17, my parents and family members arranged my marriage, and my dream of being a doctor was crushed. At 38, in 1995, I decided to go back to school after being a businessperson for 15 years. In the succeeding years, I separated from my husband and filed for divorce. Today, I am honoured to be a nurse educator and a researcher working toward a doctorate in nursing. My constantly shifting and evolving experiences and location as an immigrant woman have shaped the approach and interpretations that I have carried throughout this inquiry.

In 1984, when I was 27 years old, my mother passed away of breast cancer at the age of 49. Later, I realized that she might not have had anyone to speak to about her fears of this illness and of death and dying. She was not fluent in English, so she relied on her family for interpretations. How do you tell your mother that she is *not* going to live past 50? How do you communicate this to your father, who has been her husband for 30 years, or to your sisters, who are also her daughters? At the time, I asked the doctor whether my mother knew, and her statement is still vivid in my memory: "She is a smart woman, she knows. I have told her that we cannot do any more treatments." The nurses and doctors assumed that the family would provide interpretation and support in relation to her medical condition; however, they neglected to question contextual factors, such as socio economic status, societal expectations, the patient's expectations, or the family dynamics.

Today, as a health care professional, I agree with Doane (2003) that our work as oncology or community health nurses is about creating opportunities for nurturing relational experiences — the kind of support that we hope for with all clients but that might or might not happen or be created in a family. Within the larger social realm of life/death and illness, it is important for health care teams to critically assess complex

factors within health professional–client relationships, family and social relations, and their influences on the clients while they are journeying through their treatments and illnesses within the context of their daily lives (Bergum & Dossetor, 2003; Choudhry, 2001). This experience with my mother is ever-present with me, and I bring it to nursing and caring for patients, to research and education, and to life as a mother, grandmother, sister, and confidante for friends who are journeying through cancer. I believe these overall life experiences have shaped my nursing practice and help me to create an environment that allows for provision of respectful care within health professional–client relationships. I believe that even if relationships are brief or transitory, the quality, respect, and openness of this meeting creates a positive or a negative charge that serves as a potent source of power and is, one hopes, respectful (Hartrick, 2001; Wheatley, 1994).

My positioning as a nurse-researcher is juxtaposed against the deeper stirrings of my experiences of migration and transition along with the loss of our mother to breast cancer. I am a Canadian immigrant woman who has struggled to keep true to the traditions, beliefs, and values that were instilled in me. I have journeyed alongside my family as our mother lived through her illness experience of breast cancer and its related treatments. Therefore, in light of my identity and journey as part of a South Asian immigrant family who lived through the process of immigration and transition along with the family illness experiences of cancer, I put forth the argument that merits this proposed study.

## Summary

The demographic trend for immigration to Canada, and to British Columbia in particular, is clearly linked to the need for research into the context of health and illness for

immigrant women. It is important to recognize that an experience such as immigrating to a different country and adjusting to a new way of life affects people of all ages, backgrounds, and genders. Furthermore, there is a need to understand how immigrant women's experiences of respect within health professional–client relationships could help to alleviate distress during illness experiences, and how it could promote health and well-being for immigrant women and their families (Deeny & McGuigan, 1999; Moyle, 2003). In light of this evidence, a critical examination of health professional–client relationships within the socially constructed health care setting of a cancer agency will help to illuminate those factors that could help or hinder the development of respectful relationships.

This dissertation is organized into several sections. In Chapter 2, I present a literature review that includes respect as a concept, a discussion of the theoretical approach, and a review of the current literature on health professional–client relationships and respect, health care in a culturally diverse society, immigrant women and Canadian society, and immigrant and South Asian women's lives and cancer. The methodology used in this study, including data collection and analysis methods, is discussed in Chapter 3. Findings of the study are presented in Chapter 4 and include a description of the participants and the themes arising from the analysis. Chapter 5 includes a discussion of the findings with current literature along with the limitations and the strengths of the study. Finally, Chapter 6 includes the summary and recommendations.

# CHAPTER TWO

# LITERATURE REVIEW

I conducted a comprehensive electronic search using the following databases: Comprehensive Index of Nursing and Allied Health (CINAHL), Psychological Abstracts, Social Sciences Citation Index, Medline, and Cancer Literature. Searches were limited to the past 15 years. For the purpose of this literature search, the following key words were used: health professional–client, nurse-patient, doctor-patient, and interprofessional and interpersonal relationships; women and cancer; immigrant women and cancer; Asian and South Asian women and health care; emigration and immigration and health care; and respect within health professional–client relationships.

I begin this chapter with an overview of respect as a concept with a view to demonstrating how it is discussed and presented within the literature. A discussion of Thayer- Bacon's (2003) relational theoretical approach, its assumptions, and its application to the content of the literature follows. Finally, a review of current literature on health professional–client relationships and respect, health care in a culturally diverse society, immigrant women and Canadian society, and immigrant and South Asian women's lives and cancer will be presented.

## Respect

According to the *Webster's College Dictionary* (Costello, 1996), the noun *respect* is defined as the giving of particular attendance, high or special regard, and expressions of honour or esteem. As a verb, to "respect" is to refrain from violating, to treat with consideration and regard, and to feel or show deference and honour. The concept of respect is rooted in the core value of human relations; for this reason, other related

concepts within interpersonal relations, such as dignity and autonomy, have been used in the literature synonymously with respect to explicate the ethical dimension of respect (Peters, 1961; Rokeach, 1979). Although the foundation of nursing care and nursing principles and values such as autonomy and dignity have been built on the concept of respect (Fredericksson & Erickson, 2003; Kim, 1983; Klutgen, 1995), these concepts (i.e., autonomy and dignity) are different from respect. For the purpose of this study, I will focus on the concept of respect within interpersonal relations.

Browne (1993, 1995, 1997), who has conducted studies examining patients' perceptions of respect within health professional–client relationships, has indicated that respect is a fundamental concept within nursing, permeating a number of other concepts that are part of purposeful nursing care within the process of nurse–client relationships. However, if we wish to predicate our practice on showing or experiencing respect, a further clarification of the concept is required within nursing's body of knowledge.

There is limited research addressing the concept of respect from the client's perspective in relationships between health professionals and clients, let alone research specifically directed at Canadian immigrant or South Asian immigrant women's healthcare. The notion of respect in these relationships is entrenched in the broader context of the processes of relationships between professionals and clients in general, along with the philosophical and ethical foundations of respect. To explicate the concept of respect from the patients' perspectives further, researchers need to explore South Asian women's experiences and perceptions of respect within health professional–client relationships.

*Respect as an Ethical Principle*

In moral philosophy, respect is identified as an ethical principle and a moral attitude that reflects the inherent values of equality, human dignity, autonomy, and self-determination for all persons (Downie & Telfer, 1970; Milne, 1986; Rokeach, 1979). Hill (1982) has noted that the core idea of Kant's moral theory of humanity is that respect is something more than moral ideals and material benefits, more even than such benefits as are offered in a charitable spirit or from recognition that it is owed within relationships. The notion of "moral law" suggests that Kant's grounds for making "universal respect so central in his ethics is his belief that everyone will, inextricably 'find' that this moral predisposition commands their respect wherever it is found, even in those who flagrantly fail to follow it" (Hill, 2000, p. 93).

Milne (1986) has summarized Kant's perspective of respect as a humanity principle that recognizes humans as autonomous agents who have inherent, intrinsic values of respect by nature. Downie and Telfer (1970) hold that respect is clearly different from honour, self-esteem, and admiration, as these accolades are generally credited to those who have performed some feat or deserve respect because they have earned it, whereas respect should be attributed to everyone simply because they are human. Respect has been discussed as an ethical and moral concept of care that addresses the values of human dignity in the nursing discipline (Benner, 2002; Carper, 1979; Howard, 1975; Milton, 1994; Oberle & Tenove, 2000; Tarlier, 2004); however, research examining the client's perspectives of respect as an ethical principle of care, especially within Canada's diverse population, is nonexistent.

### *Respect as a Component of Relationships*

Lawrence-Lightfoot (2000) has argued, "Respect creates symmetry, and connections in all kinds of relationships, even those such as teacher-student or health professional–client, which are commonly seen as unequal" (p. 77). I agree that respect is not automatic in certain relationships; rather, it is an expression of circumstance, temperament, or culture. Furthermore, I contend that it is impossible to do the work that health professionals do without offering respect, thereby creating a relationship with respect at the centre (Bergum & Dossettor, 2003; Duarte Enes, 2003). McDougall, Lasswell, and Chen (1980) have defined respect as the core value of human rights, whereby individuals honour each other's freedom of choice, worthiness as humans, and opportunities for equality. Downie and Telfer (1970), on the other hand, have suggested that persons are essentially self-determining and rule following, thereby ascribing that a person must choose for him or herself what to do; even if someone tells him or her what to do, he or she still has to decide whether to obey. In literature related to health care, respect is usually described as an essential dimension of health professional–client relationships (Browne, 1997; Davis & Aroskar, 1991; Erlen, 1998; Howard, 1975; Kelly, 1992; Tarlier, 2004).

The Canadian Nurses Association (CNA) *Code of Ethics for Nursing* (2002) identifies respect as the needs and choices of clients. It is considered to be the foundation of nurse-client relationships. Furthermore, respect is one the three principles identified in the concept of justice in the CNA *Code* and is a value identified as "respecting the rights of others" (p. 5). Lawrence-Lightfoot (2000) has stated, the traditional view of respect, though rarely expressed in its pure form, tends to be relatively

static and impersonal and is usually seen as involving some sort of debt due people, because of their attained or inherent position, their age, gender, class, race, professional status or accomplishments (p. 9). I will address current literature on health professional–client relationships and respect after this next presentation on the theoretical framework of relational epistemology.

## Theoretical Framework

Thayer-Bacon's (2003) relational epistemology provides a theoretical direction for this study. This perspective enables examination of the larger socially constructed world, which has an impact on the everyday lives of South Asian immigrant women and health professionals within a clinical setting.

### *Relational Epistemological Theory*

Relational epistemological theory (Thayer-Bacon, 2003) provides a pragmatic social feminist perspective, which calls for active engagement aiming at democratic inclusion, joining theory with praxis, and striving for awareness of context and values, whilst tolerating vagueness and ambiguities. The relational epistemological approach contends that instead of continually arguing over who is right and who is wrong, we should ask how we might establish the conditions under which people might relate peaceably by probing beneath the surface of individual actions to find both causes and solutions.

Thayer-Bacon (2003) explained,

Relational epistemology offers us a relational account of human interactions with the world—its objects, fellow humans, ideas, and events. A relational approach avoids the most troubling errors of both individualism and communitarianism. Before

individuals, communities, or sub-cultures come into existence; there is a relation-encounter and response. Relation is ontologically basic. (p. iv)

Relational epistemological theory views knowledge as something that is socially constructed by embedded, embodied people who are in relation with each other (Thayer-Bacon, 2003). Relation in itself signifies a dynamic and functional interaction, a connection of beings and logical extensions of the terms of a relationship. As people have experiences with each other and develop ideas, understandings, and meanings about these experiences, they begin to construct knowledge. Relationships can be personal, one-on-one exchanges, as between a teacher and a student, a parent and their children, or a health professional and his or her client. Proponents of the theory argue that the relationships we experience with others are both personal and social. In other words, they are transactional relationships. This further augments the assumption that we are first and foremost all social beings, who are greatly affected by others but who also greatly affect others with our individual influence right from the beginning (Thayer-Bacon, 2003).

### *Assumptions of Relational Epistemological Theory*

The first assumption of relational epistemological theory is that (a) all people are social beings and that our lives begin and are lived in relationships with others. The quality of our relationships directly affects our ability to develop a sense of self, because we develop this sense of self through our relationships with others, especially if the relationships we experience are caring ones. Next, (b) we have to consider the context of the relationship, as we are contextual social beings and interpret the world through our unique contexts, our environment, including our social environment. The third assumption is that (c) we are all social beings who can learn from others, because we are

able to develop caring relationships based on such qualities as trust, respect, and autonomy. Therefore, given the assumption that we are contextual social beings who are not all knowing, I agree with Thayer-Bacon (2003), that human beings learn from each other within interpersonal relationships. In addition, meanings are socially constructed with the development of interpersonal relationships.

## Health Professional–Client Relationships and Respect

A review of the literature indicates that respect is a fundamental concept in the nursing profession (Carper, 1979; McGee, 1994; Milton, 1994; Stephen, 1994; Tarlier, 2004) and, more generally, within all health professional–client relationships (Hack, Degner, & Dyck, 1994; Morris, 1997; Oberle & Tenove, 2000). Various studies have provided substantive data on respect when addressing the process of therapeutic nurse-client relationships (Forchuk, 1995; Forchuk & Reynolds, 2001; McLeod & Schwartz-Aiken, 2000; Moyle, 2003; Rogers, 1996), and Kelly (1987, 1990, 1991, 1992) has provided data concerning definitions of respect by exploring undergraduate nursing students' perceptions about the profession's ethical values when providing care. However, there is limited literature that examines the experiences of being respected from the patient's viewpoint in multicultural clinical settings (Browne, 1993, 1995, 1997), specifically immigrant women's experiences and perspectives. These aforementioned nurse-researchers have highlighted that limited research on respect might be due to the fact that the fundamental notion of respect is difficult to define because of its complexity within interpersonal relationships, especially in a diverse society.

McGee (1994) has underlined that although respect emerges as a fundamental and essential aspect of nursing practice, there are no instruments or criteria for measuring or

evaluating it. Browne (1993) has conceded that initially, the effort of defining respect might seem rhetorical and its meaning often implicitly assumed. Browne (1995) used an ethnographic approach to explore the meaning of respect from the perspective of a Cree-Ojibway First Nations group in Northern Manitoba by examining the occurrence of respect as conveyed to Cree-Ojibway patients by nurses and physicians during health care interactions.

In her study, Browne (1995) interviewed 5 key informants who were fluent in English but spoke a Cree dialect as their first language. Although Browne (1995, 1997) identified her position as a community health nurse and felt that she contributed to the rapport process of ethnographic interviewing in both of these studies, a Cree-Ojibway native researcher conducting the interviews in Cree might have identified different meanings of respect, because participants might have been able to be more graphic and specific if they had chosen to speak about respect in their first language. Browne (1995) concluded that respect is an essential concept for nursing and that the qualities of respect reflect ethical concerns. The six characteristics of respect that emerged as findings in her study reveal the ethical aspect of respect within interpersonal relationships: (a) treating others as inherently worthy and equal, (b) acceptance of others, (c) willingness to listen to others, (d) genuine attempts to understand another and his or her situation, (e) attempting to provide adequate explanations, and (f) sincerity during interactions.

In a later study, Browne (1997) examined the ways in which health care providers conveyed respect to patients during cross-cultural interactions in clinical settings. She further explored patients' perspectives of respectful care within cross-cultural interactions. Browne reported that clinically based descriptions helped to

translate the abstractness of respect into identifiable patterns of behaviour, actions, and attitudes. In her analysis of contrary cases, she reported the characteristics of interactions lacking respect as health professionals' (a) conveying discriminatory attitudes, (b) failing to consider the patient's perspective, (c) failing to provide privacy for patients, (d) failing to provide adequate explanations, and (e) demonstrating negative nonverbal behaviours. Browne (1993, 1995, 1997) concluded that understanding the range of social, historical, and political factors that affect health care interactions is vital if health care providers are to prevent the discrimination and dehumanization that marginalized patients can encounter when entering the mainstream health care system.

Kelly (1987, 1990, 1991, 1992) used grounded theory to explore nursing students' perceptions of professional ethics and values when providing care. Kelly (1987) reported that the components of respect fell within three major categories: (a) respect for the human dignity and uniqueness of a patient, (b) respect for a patient's autonomy or self-determination, and (c) acceptance of a patient's values, even when the nursing and health care team disagrees in terms of treatment or lifestyle. These studies did not examine the concept of respect within health professional–client relationships; rather, Kelly explored students' perceptions of care as part of professional ethics and values. Even though Kelly (1991, 1992) reported respect and caring to be the ethics and essence of the nursing discipline, and provided several propositions delineating the relationships among the concepts of respect, caring, and nursing, these studies did not examine respect from the patients' perspectives.

Other related studies have examined the uniqueness and processes of being in nurse-client relationships (Forchuck, 1995, Forchuck & Reynolds, 2001, McLeod &

Schwartz-Aiken, 2000; Moyle, 2003). Moyle examined the therapeutic effectiveness of nurse-patient relationships and found that nurses' attentiveness and their ability to be with the patient decreased the distress level, thereby increasing patients' feelings of being nurtured while being hospitalized. In contrast to being nurtured, feelings of not being nurtured were reported when nursing care was focused more on the physical state, rather than the emotional state. Moyle reported that further research is needed to identify the essential components of such therapeutic relationships to ensure the validity of such research. Forchuk and Reynolds (2001) reported that clients' views of helpful relationships with nurses could cross some cultural boundaries when they compared the results of two studies, one conducted in Scotland, United Kingdom, and the other in Canada. However, the study compared nurse-client dyad relationships in psychiatric settings in the two countries but neglected the nurse's perceptions within these relationships, which would have enriched the findings, especially within dyad relationships.

Health-related disciplines, including nursing, medicine, the counselling professions, and social work, all identify respect as a central ethical principle that guides clinical practice (Beauchamp & Childress, 1994; Benjamin & Curtis, 1992; McMurchy & Vujicic, 2001; Morris, 1997; Tarlier, 2004). McMurchy and Vujicic, and Morris have used quantitative approaches to examine the patient-provider relationship from the physician's perceptions rather than using qualitative approaches to explore patients' experiences in natural settings. Morris's objective was to compare the differences among clinics and programs in the amount of respect shown to patients. In other words, Morris measured respect and its meaning as an element of patient care using a clinical

observation record survey, which was self-administered and measured patients' satisfaction of respect within relationships. These quantitative studies are limited because of their inability to elicit patients' experiences, which are located in their naturalistic settings. However, data from such studies can be used to design future studies that examine respect within health professional–client relationships in clinical settings. In other literature related to health care delivery, results have described respect as an essential dimension of humanized health care (Cowin, 2002; Davis & Aroskar, 1991; Erlen, 1998; Howard, 1975; McGee, 1994).

Related studies that have examined the value of patient-caregiver relationships with cancer patients have identified the benefits of maintaining and developing caring and respectful interpersonal relations with patients who are going through a cancer experience (Bakke & King, 2000; Dedier, Penson, Williams, & Lynch, 1999; Deeny & McGuigan, 1999; Fitch, 2000; Gray et al., 2000; Halldorsdottir & Hamrin, 1997). Although these studies have identified the importance of building trust and respect as part of the stages within relationships, I found no qualitative studies that examine the experiences of being respected from cancer patients' perspectives, let alone from the perspectives of immigrant women living in a culturally diverse Canadian society.

## Health Care in a Culturally Diverse Society

Health professionals continually face challenges when working with culturally diverse populations in constantly changing health care settings. Challenges include finding ways to communicate effectively, building and maintaining respectful relationships with patients, and providing care and support to individuals with differences that might be unique to them (Rogers, 1996). Health care encounters and dynamics that

constitute and shape these relationships are significant, as they reflect, influence, and construct social, political, institutional, and ideological relations (Browne & Fiske, 2001). The current health care system, sociopolitical milieu, and institutional settings have witnessed remarkable restructuring, downsizing, and change in the past decade, and these have strongly influenced interactions between nurses and women patients from culturally diverse populations (Browne & Fiske, 2001; Kirkham, 2003; Lynam, Henderson, et al., 2003; Varcoe & Rodney, 2002). Although these aforementioned studies have contributed greatly to Canadians health care research in hospital-based clinical settings, no studies have taken a critical perspective in examining immigrant women's experiences of being in health professional–client relationships while journeying through cancer.

Research indicates that institutional, sociopolitical, and biomedical ideologies cannot be labelled as cultural barriers but need to be examined as the intersections of social conditions within the institutional setting (Ahmad, 1993; Das, 1994). Lynam, Henderson, et al. identified that nurses face great challenges in settings where organizational supports that facilitate the prompt mobilization of clinical resources to respond to changing patient conditions and meet the patients' needs within the current health care system are not in place. This is an illustration of how nurses working in clinical contexts are personally continuously absorbing the challenges involved in providing respectful health care to an increasingly diverse Canadian population.

The ability to negotiate successful intergroup nurse-patient relationships is further complicated within the current institutional and clinical settings by diminished resources, workplace restructuring, increased demands on nurses' time, and a lack of coherent organizational support for their work (Cushing & Lewis, 2002; Lynam, Henderson, et al.,

2003). Spitzer (2004) reported on staff's frustrations when nurses encountered new mothers who did not speak English or foreign-born women who spoke English but found it difficult to express themselves in the midst of delivery or postbirth because English was their second language. Her findings indicate that although "interpreter services are expanding as an on-site service in some institutions, off-site interpreters are often required for some languages where the service is not yet available" (p. 499). Furthermore, there is often great variation in translation services when staff with varying degrees of competency is employed.

In discussions of the micropolitics of belonging in hospital settings, Kirkham (2003) found that under ideal conditions, intergroup encounters illustrated connected care marked by respectful interpersonal connections and an understanding of the illness experience from the patient's perspective. However, a lack of organizational resources, such as adequate language services, militated against connected care, especially for those patients who did not speak English, whose care was therefore compromised. Under ideal conditions, all health professional–client relationships, including those with immigrant or non-immigrant women, would illustrate respect marked by satisfied interpersonal relationships, an understanding of the illness experience from the patient's perspective, and knowledge of their health care needs (Sherwood, 2000). However, because we live in the real world and have constantly to hold the macro and micro levels of the health care system up for scrutiny, researchers must be critical in their approach to the shifting, contradictory, and ambivalent nature of health professional–client relationships.

## Immigrant Women and Canadian Society

Geertz (1973) has defined culture as representing a set of shared symbols that give meaning to people's social actions and their social world. Later, Hall (1994) defined it as a complex and dynamic aspect of individuality, not something static that each member of a community will possess. However, in present-day Canadian society, with its evolving migrant and immigrant populations, the notion of culture is identified as a complex network of meanings enmeshed within historical, social, economic, and political processes, which is constantly evolving depending on a person's daily life experiences in his or her social world (Anderson & Kirkham, 1998). Appadurai (1996) has offered a new framework for the concept of culture by examining the current epoch of globalization, characterized by images of lifestyles, popular culture, and self-representation within the larger social world. In other words, culture is not static but fluid because of personal experiences, which are learned and shared within the context of a community.

Other authors have examined health professional–client relationships in light of providing health care for a culturally diverse Canadian immigrant population (Hilton et al., 2001; Kirkham, 2003; Lynam & Young, 2000; Varcoe & Rodney, 2002). These health care studies employed a critical ethnographic approach and examined "constraints in women's everyday lives and their management of chronic illnesses" (Lynam & Young. 2000, p. 16). Hilton et al.'s study indicated that family, the nature and severity of illness, personal experiences, beliefs, and the feasibility of using traditional ways of medicine affected the use of traditional health practices. South Asian immigrant women did not

usually reveal the use of traditional practices when integrating them with Western medicine because of fear of being ridiculed by health care professionals.

Although most Canadian women will confront various challenges in feeling respected within nurse-patient relationships, these challenges are usually heightened for immigrant women (Elliot & Gillie, 1998; Harding, 2003; Hilton et al., 2001; Spitzer et al., 2003). Immigrant women might be struggling with migration and resettlement issues, which include challenges of maintaining lifelong beliefs and practices, leaving their extended family behind in their country of origin, and the responsibility of caring for other family members while learning how to establish a stable life in the new country (Bhachu, 1996; Choudhry, 2001; Kirkham, 2003). These challenges cannot be glossed over as lifestyle, behavioural, or cultural issues; rather, they are manifestations of the complex interplay of social, political, economic, transitional, and ideological contexts that will influence how interactions between health professionals and immigrant women are structured and constructed.

An examination of multiple cultural, societal, personal, and institutional factors provides a lens through which to examine the complexities of health professional–client relationships within the much broader notion of human relations (Browne & Fiske, 2001; Harding, 2003). This helps illustrate how these are orchestrated within an institutional setting, when professionals and recipients enter the relationship. For example, there might be predetermined assumptions made by nurses, physicians, and other health professionals that immigrant women expect different dimensions of respect than women from the dominant group. Fundamentally, the goal will be to go beyond simply describing pictorially a situation in nurses' and immigrant women's everyday world, and instead to

problematize and reflect on not just the power relations of social justice and structuring but also on the sociopolitical, institutionalized setting and ideologies of the health care system (D. G. Smith, 1994). Researchers who have studied immigrant women's access to health care within the context of sociopolitical, institutional, and biomedical ideologies have suggested that our theories will have to leave room for the intersections within the constantly shifting, evolving, and contradictory nature of intergroup relations under existing social conditions (Browne, 1995; Browne & Fiske, 2001; Kirkham, 2003; Lynam, Henderson, et al., 2003).

## Immigrant Women and Cancer

Studies conducted with immigrant women on cervical cancer screening have indicated that beliefs and attitudes, language barriers, socioeconomic status, and a lack of awareness of the need for regular screening practices for cervical cancer were common barriers to screening, depending on the rate of acculturation of immigrant women (Berman, Bastani, Nissenbaum, Henneman, & Crane, 1994; Bottorff, Balneaves, et al., 2001; Gupta et al., 2002; Hislop et al., 2003; Naish, Brown, & Denton, 1994). Studies on breast cancer detection practices of South Asian women and their knowledge, attitudes, and beliefs indicate that the infrequency of visits to their physicians due to the health professional's gender became barriers to screening among underserved groups (Bottorff, Johnson, et al., 1998; Choudhry, Srivastava, & Fitch, 1998; Pham & McPhee, 1992; Rajaram & Rashidi, 1999). Although these barriers impede some women's access to appropriate health care, researchers have also reported that cultural beliefs, attitudes, and values intersect with gender and social class to influence women's ability to access health care (Bottorff, Balneaves, et al., 2001).

Furthermore, for ethnocultural groups, common barriers to Papanicolaou smear (Pap) testing for cervical cancer screening include lack of knowledge, fear of pain and discomfort, embarrassment, language barriers, lack of transportation, constraints of time, lack of female health care professionals, and negative health care encounters (Bottorff, Johnson, et al., 1998; Choudhry, Jandu, et al., 2002; Thorne, Harris, Hislop, & Vestrup, 1999; Tomaino-Brunner, Freda, & Runowicz, 1996).

Related studies with immigrant women from diverse countries of origin have stated that cancer illness experience might be coloured by difficulties related to the immigration experience itself as well as to living in a different culture (Bottorff, Johnson, et al., 1998; Hislop et al., 2003; Singh, 2002). These difficulties include a wide range of stressors, such as financial burdens, uprooting and resettlement experiences, challenges in providing adequate health care for their family members, and maintaining activities of daily living (Anderson, 1987; Anderson, Blue, et al., 1998; Choudhry, 2001; Lipson & Meleis, 1985).

## South Asian Women and Cancer

Two studies have focused on South Asian women residing in urban settings in Canada and their experiences related to Pap smear access within the Canadian health care system (Bottorff, Balneaves, et al., 2001; Fitch, Greenberg, et al., 1998). Findings of both studies indicate that women experienced difficulty discussing female health concerns and felt uncomfortable in obtaining Pap smears, particularly from male health care providers. One woman stated, "I would like a place where I could go and just get it done. My doctor knows me too well. I would like a stranger to do it" (Bottorff, Balneaves, et al., 2001, p. 328). Religious requirements for some South Asian women meant that it was

inappropriate and improper for them to be examined by men or to remove their clothing in front of them (e.g., baptized Sikhs) (Bottorff, Balneaves, et al., 2001; Kernohan, 1996).

Despite some similarities in the findings of these studies, it is important to recognize the diversity among South Asian women. Health-seeking practices and experiences vary depending on women's degree of acculturation, socioeconomic status, education level, and health care experiences in their home countries. Furthermore, the influence of structures in the health care system needs to be recognized. For example, in the case of Pap testing, South Asian women's access to cervical screening is restricted not only by their health beliefs and beliefs related to screening but also by a complex interplay between social class and values, gender preferences, and the structures within the health care system (Bottorff, Balneaves, et al., 2001; Choudhry, Srivastava, et al., 1998; Gupta et al., 2002). Researchers report that for many South Asian women, asking their family physician for testing was unthinkable. They were adamant that they did not want internal examinations done by male physicians, whereas other women who had long-standing positive relationships with their physicians reported no gender preferences when accessing Pap testing (Bottorff, Balneaves, et al., 2001; Fitch, Greenberg, et al., 1998; Kernohan, 1996). However, in a study that included a small number of South Asian women, personal advice from a general practitioner or a primary doctor was reported to play a key role in women's accessing Pap screening (Seow, Wong, Smith, & Lee, 1995).

**Summary**

Respect is a basic moral principle and human right that is accountable to the values of status and equality between persons, human dignity, and inherent worthiness of a being. As evidenced throughout this chapter, although respect is an important ethical

component within health professional–client relationships, it has not been examined extensively from the clients' perspective. Health professional–client relationships play a key role when patients, especially those who might be vulnerable because of outside immigration and transition experiences, visit clinical settings, which is a further burden for those who are living with cancer. Respectful health professional–client relationships are vitally important for clients of all ages, cultures, and genders because of the therapeutic and healing nature of being in such relationships (Dillon, 1992; Forchuk, 1995; May & Purkis, 1995; Moyle, 2003). Variations in client's needs due to differences in their illness experiences, gender, and cultural beliefs and values should still be at the forefront for clinicians when working with clients of any ethnicity. Evidence provided here warrants the need for exploring respect within health professional–client relationships with South Asian immigrant women, especially to understand the different meanings of respect, if any, among women with cancer. The application of knowledge from this study can then be made to similar clinical settings that provide care to South Asian immigrant women.

# CHAPTER THREE

# METHODOLOGY

In this chapter, I provide the rationale for the choice of a qualitative approach, along with the research processes used in conducting this study. The choice of a qualitative design was relevant when considering the exploratory nature of the research and the goal of understanding South Asian immigrant women's experiences and perceptions of respect within health professional–client relationships. In this inquiry, focused ethnography (Morse & Field, 1995; Roper & Shapiro, 2000) was the principal method guiding the research design; whereas, Dorothy E. Smith's (1987) critical feminist standpoint perspective informed the methodological approach.

## Qualitative Research

Harding (1995) has asserted that the selection of a research design is not a technical choice but one that represents an ethical, ideological, social, and political activity. Research design, which is created by the researcher, is moulded by the method and is receptive to the context of the setting and the participants' experiences (Morse & Richards, 2002). Qualitative inquiry documents peoples lives, experiences, feelings, perspectives, and behaviours, locating these events in a larger social and cultural context (Ellen, 1984; Geertz, 1973). Methodological congruence in qualitative approach is acquired by ensuring the fit between the research problem, the question, the method, data analytical techniques, and the researcher's worldview (Charmaz, 2004). I view experience as connected to meanings of basic human activities. Working on the assumption that people are experts about their own experiences, I chose a focused ethnographic (Morse & Field, 1995) approach and D. E. Smith's (1987) feminist standpoint perspective for this study.

## *Ethnography*

The classic ethnographic approach of research, going out into "the field" to observe and describe a group of people within their natural setting, was one of the first methods to evolve within the cultural framework of anthropology (Agar, 1986). Over time, within the context of multiple influences and disciplines, ethnography has become multiparadigmatic (Atkinson & Hammersley, 1994; Hammersley & Atkinson, 1995). For example, critical social theory, feminism, poststructuralism, and postmodernism have expanded the scope of ethnographic research (Clifford, 1986).

Ethnography, a naturalistic approach, can be viewed as a researcher's inquiry into the subjective quality of a social phenomenon to interpret and search for social meanings within cultural norms, culturally patterned behaviours, and cultural contexts of individuals and social groups from the insider's point of view (Brodkey, 1987; Morse & Field, 1995). To provide thick descriptions or rich narratives of participants' experiences, which is the main goal of this qualitative approach, ethnography employs participant observation, field notes, and face-to-face interviews as the principal sources of data (Morse & Field, 1995; Spradley, 1979). Other sources of data include documents, records, videotapes, photographs, and maps. This interpretive stance has been used widely to guide research in the discipline of nursing (Fetterman, 1998).

### *Ethnography and Nursing Research*

Today, ethnography is used broadly in health care research as a means of understanding individuals' experiences of illness, their health beliefs and practices, and patterns of behaviour within the social context of their lives (Aamodt, 1991). As Charmaz (2004) has stated, conducting ethnographic research should be aimed at "learning about

tacit actions and implicit meanings…looking at the logic of the person's experience and entering the liminal realm of experience" (p. 988). Therefore, to understand the concept of respect within health professional–client relationships from South Asian immigrant women's perspectives, I consider it necessary to access the insider, or emic, rather than the outsider, or the etic, viewpoint. Ethnography, specifically focused ethnography, was the best fit for this proposed study.

*Focused Ethnography*

Multiparadigmatic views of ethnography have influenced ways of doing ethnography in nursing. Focused ethnography has evolved to become more clearly delineated for conducting contextually situated studies within health care research, especially in the discipline of nursing. Focused ethnography has been labelled "focused" by Morse and Field (1995), mini ethnography by Leininger (1985), and micro ethnography by Werner and Schoepfle (1987).

Knowledge generated from focused ethnographic studies is expected to have practical application to nursing practice, because this method focuses on a previously identified distinct problem within a specific context and is limited to particular times or events that occur within a small group of people (Morse & Field, 1995; Muecke, 1994). These principles allow studies to be done in a shorter period than a classical ethnography would normally require. Therefore, the use of focused ethnography as the principal method guiding this proposed study informed by a feminist standpoint perspective was a practical choice.

### *Feminist Standpoint Perspective*

D. E. Smith's (1987) feminist standpoint perspective involves directing the inquiry into the actualities of people's lives, beginning with the subjective interpretations of their experiences as grounded in their everyday material conditions. When using a feminist approach and perspective, forms of knowledge considered legitimate include experiential, subjectively derived, and intersubjective perceptions of people's lives (Harding, 1991). Fundamentally, the goal in this study was to be critical in analysis and to go beyond simply describing a health professional–client situation by problematizing and reflecting on the power relations of social justice, political, and economic factors within an institutionalized clinical setting (D. G. Smith, 1994; Thayer-Bacon, 2000). Such an examination provided a lens into the complexities of health professional–client relationships, including respect, within the much broader notion of human relations and illustrated how relationships between professionals and client recipients are orchestrated within a clinical setting.

Focused ethnography and feminist standpoint perspective were used to critically examine the assumptions and expectations of South Asian immigrant women and their experiences of respect within health professional–client relationships in the clinical setting of a cancer agency. My aim was to examine respect, which is a positive component of health professional–client relationships.

Selection of a feminist standpoint perspective was also influenced in part by the findings of my master's thesis on South Asian women's experiences following abnormal Pap smear results. This study revealed that because of a lack of communication due to language barriers, some health care professionals were not aware of the fear that most

South Asian women had of getting cancer (Singh, 2002). Furthermore, findings illuminated the cultural impact of having cancer resulting from stigmatization of the women and their daughters within the South Asian community. I realised in this study that the notions of immigration experiences and social, political, and institutional ideologies were part of the complexities of South Asian women's illness experiences. I also acknowledged the risk of essentializing this group of Canadian immigrant women, because I was unable to analyse the findings from a much broader perspective. A critical feminist lens facilitates the unpacking of subjectivities located at the intersections of gender, immigration experiences, and social, political, and institutional ideologies.

In the current study, a focused ethnographic approach informed by D. E. Smith's (1987) feminist standpoint perspective addressed meanings of respect from the standpoint of South Asian immigrant women and the institutional context of a cancer agency clinical setting. This approach unmasked how the relations of ruling within the social setting of a cancer clinic influenced the development and maintenance of health professional–client relationships.

### *Assumptions of the Feminist Standpoint Perspective*

D. E. Smith's (1987) feminist standpoint perspective defines *social relations* as "concerted sequences or courses of social action implicating more than one individual whose participants are not necessarily present or known to one another" that "nonetheless enter in and organize" experiences (p. 7). Although a key assumption in Smith's standpoint perspective is the socially constructed nature of knowledge and experience, this does not imply that there is a common standpoint among South Asian immigrant women or health professionals; rather, each of us comes with our own experiences to our

standpoint. This does not mean, however, that we reify the socially constructed world; rather, through our reflective processes, we place our self-identity in the hands of others, our social community, where we produce the "self" through interrelationships with our social world and our environment (Thayer-Bacon, 2003). D. E. Smith (1987) recognized that her everyday personal experiences served as the starting point amid her interactions of shared experiences with her community, thereby serving as the place to start her interpersonal relations with her environment. She used *relations of ruling* to mean a complex of organized practices, including government, law, business, professional education, and health care institutions. Therefore, given the plasticity of humans and their susceptibility to socially determined influences, it is significant that as humans we generally modify our nature at the same time as we develop our interrelationships with the social world.

My goal in this study, therefore, was to recognize the heterogeneity of experiences and to use experience as the entry point—a window—for critical analysis of the social relations of a clinical setting (D. E. Smith, 1991; Thayer-Bacon, 2000). However, taking the standpoint of "women" meant recognizing that as inquirers, we are also located in ways that bring us into determinate relations with those whose experience we intend to convey. Keeping in mind these feminist assumptions, I sought to acquire intensive reflexivity to negotiate entry into the field, minimize power differentials in interviewing and participant observation, and understand my personal biases.

### *Researcher Reflexivity*

The process of self-reflexivity represents a key issue in feminist methodology. A feminist paradigm assumes a dialectical epistemology that generally begins with data

collection (Lather, 1991). According to Lather, dialectical methodology is established through "dialogue with participants where reflexivity, design, data and theory emerge, with data being recognized as generated from people in a relationship" (p. 72). Self-reflexivity is a process by which the researcher becomes part of the research in assessing her or his social class, gender, race, and cultural assumptions, as well as beliefs and behaviours (Harding, 1995; Merton, 1973), or engages in self-critique to avoid theoretical imposition and to respect the dialogue exchange with participants in generating knowledge (Lather, 1991). Self-reflexivity, a necessity when using the feminist standpoint perspective, makes the researcher visible in the process of inquiry as a real, historical, and social individual who has her or his own interests, instead of being an anonymous figure of authority exclusively doing research work (D. E. Smith, 1991). In light of these considerations, my choice of a critical feminist standpoint perspective (D. E. Smith, 1987) provided the lens for reflexivity and reflectivity throughout the research process, including data collection, analysis, and interpretation.

A key concern in this study (and other qualitative inquiries) relates to the issue of the insider/outsider perspective, especially when researchers conduct studies within their own communities. The need for reflexivity was further heightened because I was from the same immigrant population as that being studied and also part of the professional community being addressed. There is often a tendency among researchers to believe that they know the culture, because they have been pre-exposed to the innuendos, rituals, specific social behaviours, language, health care practices, or other characteristics that are particular to the group under study (Asselin, 2003; Bhachu, 1996; Choudhry, 2001; Ganesh, 1993; Gans, 1997, 1999; Kusow, 2003; Singh, 2002). Researchers might not be

aware that they hold assumptions about the culture or the group but become aware of them when interviewing or reviewing research notes or transcripts of taped interviews (Asselin, 2003). There is a risk that these taken-for-granted cultural assumptions will limit researchers' ability to probe for deeper meanings or understanding of the phenomenon under study.

These and other concerns related to researchers conducting research within their own community were present when I did my master's thesis research with South Asian women and explored their experiences with the receipt of abnormal Pap smear results. However, to overlook my position in relation to the South Asian immigrant women who participated in this study would be to ignore my privileged role as a nurse-academic/researcher in the politics of knowledge production (Reimer Kirkham et al., 2002). Therefore, to minimize (as much as possible) the risk of speaking for South Asian immigrant women when interpreting women's experiences and perspectives, I employed several strategies.

Throughout this study, I have attempted to address these concerns by being aware of my heritage as a South Asian immigrant woman as well as a part of the nursing profession and have sought to separate or identify predetermined cultural values and beliefs by acknowledging these prior to data collection and analysis. In order to identify my predetermined cultural values and my influences as a member of the South Asian community and the nursing profession, I had a fellow student conduct an initial interview with me using the interview questions before I began the interviews with women. This helped me to see how I as the researcher described and understood respect within health professional – client relationships prior to data collection. Secondly, establishing a

connection and rapport with women by listening closely to their stories while conducting the interviews helped me to be reflective of my preconceived ideas about the phenomenon under study. This reflective process of being constantly aware of my preconceived ideas and reflecting on them during data collection and analysis helped to reduce researcher bias within the findings. In addition, being consciously aware, I have ensured that pertinent detailed pieces of data were not overlooked, thereby jeopardizing the credibility of the study (Roper & Shapiro, 2000). Furthermore, in this and other related research and dissemination of findings, I have attempted to avoid positioning myself as the expert when presenting South Asian immigrant women's voices. Rather, I have presented the women's perspectives and their experiences through the use of verbatim quotations to foreground their voices.

D. E. Smith's (1987) standpoint perspective of beginning inquiry in the actualities of women's lives has helped me to try to avoid objectifying and essentializing South Asian immigrant women as "different." Although being part of the nursing profession provided an easier access to the informants, I was careful not to exploit this advantage by advising the nurses of my intention and their role in recruitment. As I continued to grapple with these issues, my goals for this study were to uncover and highlight the contexts of South Asian immigrant women's experiences and perceptions of respect in the socially situated clinical setting. This required me to engage critically with the processes of the chosen method of inquiry and its practical steps. Now I will turn the discussion to describing the practical steps by which this study was designed, implemented, and conducted in the field.

## Study Procedures

Fieldwork activities in this study were devoted to uncovering the social forces shaping perceptions of respect that South Asian immigrant women had experienced within health professional–client relationships in a clinical setting. Research design and methods identified later in this chapter were used to elicit South Asian immigrant women's descriptions of their experiences to provide analytical insights into how respect within health professional–client relationships are influenced by wider institutional and social contexts.

### *The Setting*

The field setting for this inquiry consisted of two outpatient follow-up clinics at a cancer agency in the local area. The clinical environment and setting, the outpatient follow-up procedures, treatments for cancer, and the health care delivery policies fell under the same guidelines in both clinical sites. Similarity in the procedures, policies, and routine activities of the two sites facilitated analysis of the social context of South Asian immigrant women's experiences. There was diversity within the immigrant women population served in the two clinical sites selected, especially among the South Asian immigrant women population. Women in this study had immigrated from Fiji Islands, India, Pakistan, and Sri Lanka. This diversity increased the credibility and validity of the findings of this focused ethnographic study. Nevertheless, it was expected that these geographic boundaries would also provide some degree of homogeneity in South Asian immigrant women's previous experiences with respect.

As a nurse, I was known at the clinical follow-up settings in the capacity of a researcher employed by the cancer agency for short-term projects over the past few years.

However, I had not undertaken any prior research of my own, nor had I made any significant patient contacts or negotiations with the administrators regarding access into the cancer agency during the previous projects. As I discuss later, this provided a certain ease of access into the cancer agency and facilitated rapport with some health professionals.

### *Gaining Access*

As the study was conceptualized, I discussed its purpose and methods with several professional clinical practice nurse leaders to obtain their feedback concerning the design and the proposed involvement of nurses and other health professionals as part of the recruitment team. As the study took shape in the form of a research proposal, I sought and received letters of support by making preliminary contacts regarding fieldwork and access procedures with the administrative and nursing services of both clinical sites. The initial request for access and a letter of support from both clinical sites provided by the provincial professional practice and academic nurse leader from the agency are included in Appendix A. Verbal permission to contact the patients was followed by written ethics approval from The University of British Columbia Behavioural Research Ethics Board in conjunction with the agency's onsite co-supervisor for the study, who was a staff member, a requirement of the agency's research ethics application and approval protocols. Written ethical approval from The University of Alberta Health Research Ethics Board was sought and obtained simultaneously.

Negotiating entry to the cancer agency on receiving ethical approval for the study was initiated through discussions with the professional clinical practice nurse leader, who, in her administrative position, was keenly committed to promoting nursing research

and practice. She, along with other nursing practice leaders, was keen on supporting this study because it would inform the agency about providing the most appropriate care to the increasingly diverse patient population. In turn, she directed me to another professional clinical practice leader, who sat on the agency's research review committee. As a clinical practice leader and a researcher, this professional was able to discuss the feasibility of the study's design and proposed involvement of nurses and other health professionals.

Nursing, radiation, chemotherapy, and follow-up clinic managers were also instrumental in negotiating my access to particular units by taking responsibility for informing health professionals about the study in very general terms via group e-mails. The health professionals were therefore aware of my purpose in approaching them about potential research participants and their roles during participant observations. Following discussions with managers, particular units and patient review sessions were eliminated because of the cancer sites and advanced stage of the disease and in consideration of the emotional and physical vulnerability of some patients and families, especially those patients who were in palliative care.

Although there was a certain ease of access to the cancer agency because of my previous exposure to the clinical settings, I was naïve as to the footwork that was needed when negotiating entry. Gaining access is not always limited to requesting authorization; it implies knowledge as to from whom the authorization must be requested (Hammersley & Atkinson, 1995). Because negotiating entry into the field is a core issue in ethnographic research and required that I build credibility, I had to establish confidence with health professionals who were central to my study.

## *Sampling*

The goal of the sampling strategy was to select participants who were able to provide rich and detailed information about their experiences of respect. Purposeful sampling is generally employed to select people who have experience with the research topic (Cresswell, 1998; Denzin & Lincoln, 2000; Morse & Field, 1995). Purposeful sampling proved strategic for this inquiry, as South Asian immigrant women had to be identified by surname, language, and country of origin, regardless of the type and site of cancer. Sampling was aimed at finding South Asian immigrant women participants who were able to address research questions about their perception of respect.

### *Selection Criteria*

In qualitative studies, sampling is used to select participants, events, and observations that will contribute to the understanding of a phenomenon. The primary goal is the in-depth understanding of a phenomenon. Sandelowski (1995) also underlined that qualitative sampling is theoretically driven and that sample size must be assessed with regard to the goals of the study. Morse and Field (1995) have suggested that an adequate sample size in qualitative research is one that permits, by virtue of its not being too large or too small, a sample to achieve a new rich and thick understanding of the experience. In other words, it is difficult to determine a priori the number and kinds of participants in qualitative inquiries. Sandelowski (1995) has found that data from fifteen to twenty people—sometimes fewer—can be sufficient to provide comprehensive understanding of a phenomenon. Consequently, in this focused ethnographic study, in which I paid attention to the quality of the data generated, a suggested number of eighteen to fifteen participants was the original goal (Carspecken, 1996; Sandelowski, 1995).

*Inclusion and Exclusion Criteria*

The inclusion criteria for the study were those who (a) had been diagnosed with cancer; (b) were presently receiving cancer-related treatments or follow-up clinical visits; (c) were willing and able to share their experiences of respect within health professional–client relationships; (d) were able to communicate in English, Punjabi, or Hindi; (e) had immigrated to Canada at the age of twelve years or older; (f) had immigrated from Fiji Islands, India, Pakistan or Sri Lanka; and (g) were eighteen years of age or older.

Palliative care clients were excluded, because their experiences differed from those who were presently diagnosed with or were going through follow-up treatments for cancer. Clients younger than eighteen years of age were excluded as minors who were unable to give consent and because the younger population's cancer experiences would differ due to their ages and cancer care services provided.

Although a diverse group of Canadian South Asian immigrant women from the subcontinents of Fiji Islands, India, Pakistan, or Sri Lanka might share similar cultural practices surrounding diet and food, dress, ceremonies, and cultural norms, it was assumed that experiences surrounding personal, social, and economic factors would still differ. In light of these differences, I made an effort to include participants who differed in terms of age, religion, country of origin, and immigration history to ensure that women with a variety of experiences were included in the study.

*Recruitment*

South Asian immigrant women were recruited from two clinical settings of the cancer agency. I proposed to employ three methods in my recruitment strategy: (a) clinic charge nurses offered women the invitation letters with a choice to be included in the

study by contacting me, or, with prospective volunteers' permission, the charge nurses forwarded their names and phone numbers to me (Appendix B); (b) advertising in the local ethnic and community newspapers and newsletters of community organizations, and local ethnic community radio announcements (Appendix C); and (c) the cancer agency news bulletins (Appendix C). Neufeld, Harrison, Hughes, Spitzer, and Stewart (2001) found these strategies to be fruitful in their recruitment process; however, in their study research assistants translated the required materials into the languages appropriate for clients of each participating agency.

Although I was prepared to use all proposed methods to recruit participants, I found that methods (a) and (c) were sufficient. The cancer agency's administration office placed the advertisements on their bulletin boards. Follow-up, chemotherapy, and radiation therapy unit managers were instrumental in facilitating recruitment by asking me to attend various team meetings to inform staff about their roles and my expectations in relation to recruitment and participant observations. In response, health professionals reviewed their patient lists to help identify South Asian immigrant women by surname, with a view to identifying possible participants.

Once a potential participant was identified, the nurse or radiation therapist offered her a study package, which included a letter of introduction, a brief overview of the study, and the consent form indicating the inclusion and exclusion criteria (see Appendices B, C, and D). This information package was written in English, Hindi, or Punjabi and included my phone number and contact address, a brief explanation of the project, and an invitation for South Asian immigrant women to contact me if they wished to participate in the study.

Most of the participants chose to leave their contact numbers with health professionals; however, others phoned me directly after receiving and acquainting themselves of the study objectives. I contacted directly those participants who had chosen to leave their contact numbers with health professionals. At the time of initial contact with participants, I provided a brief verbal explanation of the study, discussed the inclusion and exclusion criteria, and offered an invitation to be included in the study if they so wished. I often discussed study details in Hindi or Punjabi over the telephone with other family members, particularly if I felt a woman was encountering difficulty understanding her role in the study. Only those participants and their families who expressed an interest by providing verbal consent were given a more detailed account of the study. After confirming participants' choice to be involved in this project, I proceeded with the interview at a place convenient to them.

## *Data Collection*

The data collection methods, including participant observation, in-depth interviews, and document retrieval, were consistent with the principles of qualitative research design. These methods are well documented in the research literature as rigorous methods for collecting rich, contextualised data (Huberman & Miles, 1998).

### *Fieldwork*

Fieldwork for the purpose of data generation in this focused ethnographic study consisted of four activities: (a) participant observation at both cancer agency settings for contextual data in relation to the milieu and activities of the clinic, (b) in-depth semistructured interviews, (c) written and tape-recorded field notes, and (d) analysis of any available related documents (agency policies and guidelines, and educational

materials for patients). This provided a natural triangulation of data about the same phenomenon (Morse & Field, 1995; Morse & Richards, 2002). I became the data collection instrument when conducting fieldwork. Although I was guided by general topics of interest and even specific questions to be answered, there were no minimal preconceived notions about the outcomes of the research (Roper & Shapiro, 2000). The questions formulated before the fieldwork began guided the research but changed as the study progressed (Morse, 1992). Fieldwork is an intensive engagement of a limited duration involving various techniques and strategies, of which "immersion" is the best-known activity (Watson, 1999).

*Participant Observation*

Beginning the study with participant observation proved effective in reducing the effect of researcher presence. Participant observation, which is a tool of inquiry in qualitative research, suggests a special form of observation in which inquirers immerse themselves in settings so that they can experience the milieu in which participants situate themselves (Ellen, 1984). Therefore, I sought to become immersed in the natural setting to grasp the depth of South Asian immigrant women's lived experiences of respect within the clinical setting. Although I was immersed in the natural setting, I did not participate in health care provision as a nurse. My role was as an observer participating only in casual interaction. I observed how health professionals orchestrated their daily routines within the clinical setting, how they integrated interpreters for provision of cancer information to non-English speaking clients, and how they interacted with clients while providing cancer care. The observations were not restricted to observing cancer care for only South Asian immigrant women, but for all the clients visiting the clinic. I observed

health care professionals interactions with clients but did not record verbatim the conversation between the health professional and the client.

Participant observation was done at both of the outpatient follow-up clinical settings. I shadowed health care professionals of each discipline at each clinic over a period of two weeks before the initiation of the interviews to observe and identify daily, routine activities within the clinical settings. Observations were limited to three or four hours per day, so that I could maintain observational concentration with accuracy (Reimer Kirkham, 2000). To observe variations according to time of day, observations were conducted on mornings and afternoons in both clinics.

On entering the client's waiting room, I obtained verbal consent and either I or the health professional gave a brief, written explanation of the study and assured the client's confidentiality. The client was advised about her right to not have me present. Participant observation was conducted before the interviews in order to provide a background for women's stories and to provide insight into how health professionals orchestrated their work with clients in the clinical settings within this particular institution. Participant observation data and field notes were analysed concurrently with the interview data in order to facilitate the understanding of health professionals' work and to provide information about context of the clinical settings. As preliminary data analysis progressed, I returned for further participant observations to clarify, confirm, and validate contextual data. Re-visiting the clinical settings at a later date provided a richer contextual understanding for women's stories of respect with health professionals at the chemotherapy, radiation therapy or outpatient follow-up units as I was sensitized to new observations. An outline of the procedures is presented in Appendix E.

The unit managers generally assigned me to particular health professionals who were aware of my nurse-researcher role at the clinics. As I accompanied the health professionals, my observations were focused not on the verbal and nonverbal interactions between clients and health professionals but on the organization, structuring, and context of the clinical setting on a workday. The intent was not to evaluate the health professional in their relationship with clients but to use participant observations as an entry point to understanding relationships in the wider context of health professionals' everyday work. Observing health professionals interacting with each other also provided important contextual data. In fact, observations during team meetings were invaluable when scarcity of resources, unavailability of spaces, and incident reports were discussed. These participant observations were recorded as field notes promptly after the observations. See Appendix E for a field notes guide.

*Participant Observation Field Notes*

The purpose of field notes was to provide a descriptive account of the natural setting in which South Asian immigrant women received health care and to record what happened in the clinical setting on a daily basis. It was unrealistic to expect that all aspects of any setting could be described, but it was important to record as much as possible while being guided by the research objectives. During participant observational sessions, I wrote field notes in short form to facilitate recall immediately after the observational sessions, when more detailed accounts were recorded.

*Interviews*

The ethnographic interview, which is situated in the social world, is dependent on the interaction between the researcher and the interviewee. It is in this interaction that

both participants and interviewees create and construct stories of the social world. Rich descriptions of social worlds are facilitated when friendly conversation is used and when the researcher slowly introduces new questions to assist participants in responding without the awareness of being the participant (Spradley, 1979). In this study, establishing good rapport between the researcher and the participant was important, especially in light of the sensitivity of the topic and the contents of the interview (Gans, 1999; Narayan, 1993). Being sensitive to women's feelings and privacy during the interviews was important, because this helped enhance rich descriptions of truthful and insightful data

*Participant rapport*. The development of rapport between researchers and participants is a key element of qualitative research and the core of feminist research methods. This dialogic and dialectical process of data collection gives room for subjugated voices to be heard. Oakley (1981) has illustrated the interactive dialogical—dialogue between the researcher and the researched—by showing that women's (feminist view) interviewing involves more than simply asking a set of questions. Engagement with, rather than detachment from, the person is valued as a part of the interview process (Hall & Stevens, 1991).

I had to be aware of the risk of imposing my views, as the goal was to let the participants express their thoughts and describe their experiences by building trust and rapport within a relationship. Developing rapport with participants was an important aspect of the research process (Reinharz, 1992). Rapport is a criterion of adequacy reflecting how well participants' experiences have been heard during an interview (DeVault, 1999; Hall & Stevens, 1991). Elements of rapport, such as trust within a

relationship, length and frequency of the talk or contact, intimacy of the setting, and the researcher's language, indicate validity of data in feminist research.

Because I am a South Asian immigrant woman, women who volunteered might have viewed me as an insider, but as the researcher, I might have been considered an outsider. The reception that I received from women was generally warm, helping to establish initial rapport and trust with women and their family members, especially with husbands or daughters who stayed for the duration of the interviews. Some authors have indicated that often immigrant populations are more open to co-ethnic interviewers, as participants can talk freely with co-ethnic interviewers, who are considered to be outsiders and might never return, because they are not part of the same community (Ganesh, 1993; Gans, 1999; Kusow, 2003; Rumbaut, 1999; Singh, 2002). This notion of the researcher being a stranger or outsider is an advantage, because outsiders bring a combination of remoteness and nearness, concern and indifference, especially if participants will tell a stranger some narratives that they would never tell each other as members of the same group (Harding, 1991; Neufeld et al., 2001).

Other authors have indicated that some immigrant groups do not seem to take ethnicity very seriously and feel more at ease with researchers who are insiders with respect to gender, age, language, and other criteria (Holstein & Gubrium, 1995; Narayan, 1993). I found during my master's thesis research that Canadian South Asian immigrant women who had assimilated easily into the Canadian culture were more open to discussing intimate details about their health care experiences with me as the researcher/interviewer. Other Canadian South Asian immigrant women in the same study who were recent immigrants regardless of age felt more comfortable talking to a member

of the same group as their own because of the sensitivity of the topic, language, and the contents of the interview (Singh, 2002).

*Interview process.* Those who voluntarily agreed to participate in the interview signed a consent form (Appendix D, cited previously), which I verbally translated into Hindi or Punjabi as necessary (Morse & Field, 1995). Translated versions of the information letter and consent form were also available for women to read before they signed the consent form. Verbal consent was audiotaped, and written consent was procured from non-English– as well as from English-speaking women. I was able to translate any details about the study for those participants for whom English was not the first language.

Initial interviews with the eleven participants were conducted in the women's homes, with the remainder taking place at another location that was convenient for them. The initial interviews in women's homes helped me understand their experiences in the context of their lives as South Asian immigrant women who generally lived with their extended families. Previous research has indicated that many patients are reluctant to speak in any depth about their hospital experiences but are more comfortable discussing these experiences in their home environment (Anderson, 1998).

The home interviews generally began with women insisting on serving me tea and sweets, which helped in establishing initial rapport and trust. At most of the interviews, other family members, for example husbands or daughters, stayed for the whole interview. As the primary caregiver, they were very involved in the women's care, especially when they accompanied their family members for the chemotherapy treatment, which could last up to eight hours for one visit. In some interviews, the daughters or older

granddaughters translated for me, because some words were difficult for the participant to understand due to the dialect of the language, especially Punjabi. Some women wished to have a family member present during their interview. For them this facilitated the interview process as they felt comfortable and supported by their family. Although there could be a concern that the presence of family members may have restricted women's ability to share their experiences of respect, the content and length of their discussions did not differ from other interviews.

It was evident that saturation of data was achieved when all eleven women provided a rich understanding of South Asian immigrant women's experiences of respect within health professional–client relationships, and related stories reflecting similar themes. In addition to saturation of data, the breadth of women's experiences was portrayed by variation in the type of cancer diagnosed and its treatment, their ages, immigration, transition and acculturation experiences, country of origin, and education levels. Four women were purposively approached and interviewed a second time so that I could elaborate on, validate, and confirm their accounts and clarify variations of any kind. Questions for the second interviews were generated from review and analysis of data from women's first interviews. These questions took the form of requests for elaboration or clarification. Women's responses were then incorporated into the data analysis to confirm and elaborate on differing or similar experiences of respect. This strategy enabled me to gain further insight that was useful in exploring and clarifying themes and aspects of the participant's experiences of respect. Browne (1995, 1997) found that interviewing informants a second time provided confirmation and validation of

the data as well as adding clarity to an understanding of the meanings of respect among women.

This strategy was also confirmed by DeVault (1999), who noted that eliciting useful accounts of women's experiences was more than encouraging women to talk—it was to "listen to their talk—clearly" (p. 95). Furthermore, by listening to the participants' experiences, the researcher can avoid filling in the missing pieces of the talk or narrative by rushing the participant during the interview (DeVault, 1999). The researcher's ability to "listen to their talk—clearly" became necessary during some of the interviews, especially when women's voices became distant, as if they were reliving the experiences of respect within the health professional–client relationship at the time of the interview.

Moreover, because I was familiar with the domain and the components of the phenomenon but unable to anticipate all possible responses to a particular question, I used a semistructured questionnaire, which consisted of questions that could be answered freely (Morse, 1992). Using a semistructured interview guide enabled me to guide the direction of the interviews and allowed South Asian immigrant women to talk about their experiences (DeVault, 1999; Morse, 1992). This strategy proved effective when I discovered information that was new or interesting while listening to the responses, giving me the opportunity to probe for additional information and discuss any of the responses further. A sample of interview trigger questions used as a guide is listed in Appendix F.

All of the interview guiding questions were piloted with two South Asian immigrant women who were ineligible for the study (did not have cancer) but were dealing with chronic illnesses. In the pilot, I began the interview by asking women to

describe or define the word 'respect'. I used this as a starting point in order to identify how they perceived respect within health professional – client relationships. However, I realised that women were more comfortable using an open approach and telling their stories living with chronic illness from the beginning of their journey which included their experiences respect within health professional–client relationship. Because this open manner of interviewing was a useful catalyst for women's reflection I revised the order and type of questions, which allowed me to elicit more detailed descriptions of women's experiences and perceptions of respect early in the interview. Revisions in the interview guide were made on the basis of the feedback obtained from women during the interview processes. The nature of the changes included variation in the order of the questions, adaptation of the questioning style because of the informant's age, or inviting elaboration in their response to some of the questions because women had more stories to share. The interview questions were also translated into Hindi and Punjabi and modified following the pilot interviews.

Both formal written and audiotaped consents to participate were given prior to the interview by all except one participant, who gave audiotaped verbal consent only, because she feared that her signature would commit her to clinical research involvement as part of this study. All eleven interviews were done face-to-face and lasted thirty minutes to an hour. I conducted and audiotaped all interviews, which were then transcribed verbatim; however, nine of the interviews done in Punjabi and Hindi were verbally translated and tape-recorded to English prior to transcription. All transcriptions of interviews were checked line by line for accuracy against the audiotaped interviews. One translator competent in Hindi or Punjabi was asked to translate and transcribe two

interviews to ensure accuracy of translation. One interview was translated from Hindi to English and the other from Punjabi to English. These were then compared with my translated version of the interviews, and I discussed any areas of discrepancy with the translator to establish consensus. Tang (1999) has suggested that checking and rechecking the translation and interpretation of the interviews for credibility and constant analysis of the incoming data and respondent validation maintain confirmability.

*Interview field notes*. I used journaling in the form of field notes to keep track of important impressions and interpretations that occurred during the in-depth interview process. Emerson and colleagues have confirmed the utility of field notes such as journal entries, which are sketchy notes and written comments of conversations or routines that are observed by the researcher (Emerson, Fretz, & Shaw, 1995). Appendix G contains the guide for field notes and journaling used as part of interview data collection.

Observation and reflection data gathered during these interviews were recorded as field notes. Ongoing field notes made during the interviews were maintained for all interviews, as tape-recorded interviews do not portray the physical setting, the interpretations and impressions of the observer, or the nonverbal communication of participants (Atkinson & Hammersley, 1994; Morse & Richards, 2002). These impressions and interpretations during interview periods supplemented audiotaped data collection and were recorded as field notes (Morse & Field, 1995). I constantly engaged in reflexivity and reflection to reduce the imposition of preconceived assumptions.

*Document Retrieval*

In this study, documents retrieved for the purpose of data analysis included educational materials that were provided to women during their clinical visits, outpatient

clinical setting policies and guidelines regarding the provision of health care, and the cancer agency's vision and mission statements and information about the urban setting. These documents have been analysed along with the participant observations in the context of the clinic's structuring and organization. A list of the educational materials and the agencies' mission and strategy plan, policies, and guidelines is attached as Appendix H. Data in the form of documents often consist of institutional policy statements and guidelines, statistics, and patient charts and records (Morse & Field, 1995). However, patient charts and records were neither available nor used in this study. These documents can be used to validate information provided by patients and health care institutions (Morse & Richards, 2002).

The purpose for analyzing the agency's vision statements, the clinic's policies, and guidelines for the various disciplines was to provide contextual information about the clinical setting. A rigorous analysis of these types of documents provided information about the clinical setting's organization and structure for the purpose of providing health care within the current health care system. This form of document data analysis supplemented participant observation by providing me with insight into what happened in the clinical setting

Furthermore, a review of the educational materials provided further insight and context into South Asian immigrant women's experiences of respect within health professional–client relationships. The unit managers and health professionals shared the educational materials generally provided for clients going through cancer-related treatments. Most health professionals voiced their concerns in relation to the shortage of language-specific material available for symptom management of chemotherapy or

radiation treatments. Some material, on female cancers, such as breast and ovarian cancer, were more readily available than those for tongue, brain, or colon cancers. As a basis for document analysis during the participant observation phase, all English or non-English written educational material pertinent to the type of cancer and treatments along with policy guidelines unique to the clinical setting were retrieved. An analysis of the written educational material available in for the clients was done in light of the type of cancer they had and the language they spoke. Furthermore, during participant observation, I observed what written educational material was being given out to clients in light of their type of cancer and its treatment. South Asian immigrant women were asked about the receipt of language-specific written educational material in relation to the type of cancer and its treatment during the interviews. This form of document analysis along with participant observation and interview data provided a rich context for understanding how health professionals orchestrated themselves in the clinical setting and women's experiences and perceptions of respect. These various documents were included in the data and the analysis (Morse & Field, 1995). Details of data analysis procedures will now be discussed.

### *Data Analysis*

In ethnographic work such as this, data collection and analysis occur concurrently, enabling modification of interview questions to elicit more in-depth information of South Asian immigrant women's experiences (Guba & Lincoln, 1994). I translated incoming interviews as necessary, transcribed them, checked them for accuracy, and corrected them before analysis began. I examined participant observation data, inclusive of field notes, concurrently with the interview data and the accompanying

interview field notes to make sense of the whole and to identify critical factors within the clinical setting that were significant (Morse & Field, 1995). A constant analysis of the incoming data was reviewed to identify recurring, converging and contradictory patterns of women's experiences, preliminary themes and categories, and illustrative examples from the data.

I catalogued data by codes, which I constantly refined by reading and rereading each interview in its entirety, then stepping back and reflecting on the whole interview and observational field notes, achieving a preliminary identification of themes in the data (Spradley, 1979). I initially coded the data line by line to identify important ideas/experiences (Spradley, 1979). Data pertaining to similar ideas/experiences were then grouped into categories. As new data were collected, I used a similar process, revising or adding to the emerging categories as required. I reviewed data related to each category to identify gaps in the data or inconsistencies that needed to be explored in subsequent interviews and observations. Related categories were synthesized so that I could identify important themes that described key aspects of South Asian immigrant women's experiences of respect. For example the theme concerning the "health professional's approach" included the related categories of "demonstrating a professional manner" and a "courteous approach". Both specific categories and more abstract themes were constantly refined as new data was generated and more in-depth analysis completed. I entered coded interview transcripts and field notes into NVivo (7), a software computer program for organizing and grouping data into sets, which can then be quickly linked for comparing and contrasting categories. Critical questioning of theoretical perspectives, my reflexive analysis, and continual consideration of participants' perspectives resulted in

participants' perspectives resulted in ongoing refinement of coding categories, concepts, and themes. Any identified gaps and inconsistencies in the data were constantly explored by being critical and reflective of the analysis ongoing refinement of categories.

By using constant comparison, and re-examining and systematically sifting through the data, I was able to identify relationships among major categories and move toward a more abstract level of conceptual analysis (Hammersley & Atkinson, 1995). Because of the complexities within human experiences that are governed by social and personal factors, South Asian immigrant women had some negative experiences of respect. I included these interviews to reveal similarities or differences in experiences.

*Establishing Scientific Rigor*

Rigor in qualitative research is demonstrated through the researcher's attention to and confirmation of information discovery. Various terms are used to describe the processes that contribute to rigor in qualitative research. Sandelowski (1986, 1993) has identified the following criteria that support rigor in qualitative research: auditability, confirmability, credibility, and transferability. However she has reminded us that no one set of criteria can be expected to fit every study.

Auditability consists of a record of processes used to collect and analyze data and memos and notes identifying the rationale for making choices in a research project (Sandelowski, 1986). The strategies used to identify a clear decision trail in this study included detailed journaling and notes of methodological choices in relation to data generation and analysis. Initiatives to enhance effective methodological procedures, such as improving interviewing skills with participants, being able to formulate better open-ended questions, and paying detailed attention to the participants' responses during data

collection, and concurrent analysis generated an auditable trail of the process and logic to be reviewed by others.

Credibility refers to the concept of internal validity and is defined as the extent to which the researcher adequately represents the informants' construction or representations of the findings (Sandelowski, 1986). In this study, credibility was achieved through the rigor of methodological and conceptual development of the research with careful documentation of contacts with the participants. I used multiple methods of data collection, including participant observation, in-depth semistructured interviews, journaling, and field notes, to complement one another and to help me grasp women's perceptions of respect. I employed this strategy of triangulation of data across data sources and data collection procedures to determine the congruence of findings among the participants.

Two interviews were checked and compared for the accuracy of the English translation and interpretation of Punjabi and Hindi taped interviews. Constant analysis of the incoming data and modifying interview questions to elicit more in-depth data helped to confirm the conceptual development of the findings. These strategies of documentation during incoming data and concurrent analysis ensured reliability of the data and provided the rationale for my conclusions.

In qualitative research, confirmability, or trustworthiness, is the criterion for rigor used to establish freedom from bias in the research procedures (Morse & Field, 1995). Prolonged contact with four women who were interviewed twice in order to provide clarity of data helped to maintain confirmability. The degree and intensity of fieldwork time spent doing participant observation was important in developing trust and providing

clarity for the multiple influences or contextual factors that might have influenced women's experiences of respect.

The process of establishing a connection and rapport with South Asian immigrant women and closely "listening" to their narratives during the interviews helped me to stay close to the participants' experiences. In addition, the process of critical writing and reflection of my assumptions and stereotypes helped me to avoid imposing my ideas and interpretations throughout data collection and analysis, thereby allowing researcher objectivity. These steps are congruent with Sandelowski's (1986) view that validity can be achieved by staying close to the participant's words and bracketing preconceived ideas about the phenomenon before beginning research.

Transferability refers to the generalizability and applicability of findings to similar populations in different settings (Sandelowski, 1986). In this study, emphasis was placed on the uniqueness and contextual situation of the setting and the human experience, which was captured by time and place. Strategies such as participant observation provided contextual data of the clinical setting where South Asian immigrant women experienced respect within health professional–client relationships. In-depth semistructured interviews provided rich descriptions of participants' stories of their experiences of respect at this particular outpatient follow-up clinical setting at the cancer agency. These methods of data collection, along with carefully detailed field notes and journaling used concurrently with data analysis, helped to provide context and insight into South Asian immigrant women's experiences of respect in that particular cancer agency clinical setting. This ensured that the findings were well grounded and reflected South Asian immigrant women's typical and atypical life experiences of respect at the

time and place of the study. In addition, participants' diversity added to South Asian immigrant women's varied experiences, which were unique to this clinical cancer agency setting and this population. The findings in this study are unique to the location, time, and population set out in this study; therefore generalizability of these findings should not be applied directly to other cancer agency settings. However, the detailed descriptions and information provided in this study could enable readers to assess their relevance for other clinical settings with similar contexts and patient population (Sandelowski, 1986).

In summary, consistent with D. E. Smith's (1991) feminist standpoint perspective, taking the experiences of health professionals and South Asian immigrant women as the starting point for inquiry does not limit the findings to the local setting. Rather, these experiences should be conceptualized as a means of understanding the wider institutional and sociopolitical issues of organizing health care experiences (D. E. Smith, 1987). I maintained the process of analytical and interpretive pathways throughout the study to ensure scientific quality.

*Ethical Considerations*

A written approval from the University of Alberta Health Research Ethics Board (Panel B: Health Research) committee as well as the cancer agency ethics committee through The University of British Columbia Health Research Ethics Review Board was obtained before data collection began. I obtained informed written consents from all participants except one, who opted to give audiotaped verbal consent as part of ethical procedures. Consent forms were in English and translated versions in Punjabi or Hindi for women who did not read or speak in English. Verbal consents were audiotaped for all of the interviews. The women were advised that they had the right to withdraw and refuse

further involvement at any time during the study. Privacy, anonymity, and confidentiality were ensured (Morse & Field, 1995). Women were assured that their health care would not be affected by their decision to participate or not participate in the interviews.

Women who needed more information about their cancer-related treatments or had questions regarding their future health care were advised to consult with their attending health professionals at the outpatient follow-up or treatment-related clinics. In case women needed advice or counselling for psychological distress related to cancer, they were advised to consult with their attending health professionals or the counsellors in the social support and counselling department at the cancer agency. I had a list of the counsellors in the social support and counselling department at the agency in case the need arose.

Data, including the audiotapes, interviews transcripts, field notes, consent forms, and computer archives, were stored in a locked cabinet for confidentiality. Access was restricted to my dissertation committee and me. Participants were not identified by name at any time during the project. In addition, they were advised about how confidentiality and anonymity in relation to the data would be preserved. The data will be retained for secondary analysis for future projects subject to approval by the research ethics review committee.

# CHAPTER FOUR

## FINDINGS

The purpose of this study was to examine South Asian immigrant women's perceptions of respect within health professional–client relationships as they journey through cancer. I will begin with a description of the clinical context of the setting; I will then describe South Asian immigrant women's experiences, their perceptions of the health professionals' approach, and their expectations of respect in their relationships with health professionals at the outpatient follow-up clinic. The findings provide insight into how respect is influenced by South Asian immigrant women's heritage and their expectations of respect in light of their frame of reference for professional relationships. Excerpts from participants' stories will be used to illustrate the women's experiences of respect in light of their cancer condition and its related treatments.

As the analysis unfolded, it became apparent that the establishment of a respectful relationship in the context of health professionals' everyday work and South Asian immigrant women's everyday lives is positioned within a personal, social, professional, and cultural location, which might be deeply ingrained with assumptions that each party makes of the other. These assumptions and expectations can create a climate of scepticism and obscurity when health professionals and South Asian immigrant women meet within the health professional–client relationship. The relational experiences of a professional and a client occur in the context of numerous cultural possibilities within the clinical setting. Observational and interview data provided an opportunity to examine how South Asian immigrant women experience respect within health professional–client relationships in the clinical context of the setting. Multiple

sources of data provided a more complete picture of South Asian immigrant women's experiences and perceptions of respect with health professionals within the clinical setting.

## Participant Profile

The sample of eleven participants in this study consisted of five from the Fiji Islands, two from India, three from Pakistan, and one from Sri Lanka. Four of the eleven women participated in second interviews. All of the women self-identified as South Asian immigrant women who were not born in Canada but had immigrated here after age twelve. South Asian immigrant women from the Fiji Islands spoke English or Hindi, those from Pakistan spoke either English or Urdu, women from India spoke mainly Punjabi, and the woman from Sri Lanka spoke English and Tamil. Religious backgrounds of these South Asian immigrant women varied from Hindu and Christian for women from the Fiji Islands, Sikh and Hindu for those from India, Muslim for women from Pakistan, and Christian for women from Sri Lanka. At the time of the interview, the women had resided in Canada for between three and thirty-one years.

Demographic profiles of the women who participated in this study showed diversity in age, number of years in Canada, education, socioeconomic status, and type of cancer. The types of cancer ranged from brain to breast, colon, and tongue, and the women had undergone either or both chemotherapy and radiation treatments. The ages of the women varied from forty to eighty, with the majority being over age sixty. Educational levels also varied widely, with four women having postsecondary level education, whereas seven had either elementary schooling or no formal education. Of the seven women who were under sixty-five years of age, only one was employed full-time.

The rest had retired or had never worked outside the home, although most of these women worked at home caring for grandchildren. Four of the eleven women had been widowed in the previous two to ten years and lived with their extended families.

## The Context of the Clinical Setting

I used the data from participant observations and documents retrieved to describe the context of the clinical setting in which health professionals practiced and South Asian immigrant women experienced respect. These findings provided a lens to the larger context of the clinical setting by describing cancer care services in the province, payment for cancer care in the setting, and a description of the cancer treatment setting where this study was conducted.

### *Cancer Care Services in the Province*

The cancer agency that served as the site for this study is a member of the Provincial Health Services Authority (PHSA). PHSA is responsible for governing, managing, and funding this cancer agency. Governed under the PHSA body, the agency acts as a public teaching and practicing hospital and has affiliated agreements with local universities for ongoing cancer-related research. The cancer agency's mandate covers the spectrum of cancer care, from prevention and screening to diagnosis and treatment, through to rehabilitation. Presently, the cancer agency has four regional centres, with a fifth scheduled to open in 2008. Each of these four regional centres acts as a host institution within the catchments of the regional health authority jurisdictions under which it falls. A list of the documents retrieved and analysed for this section is attached as Appendix H and I.

The cancer agency has evolved from the previous "geographic centre" approach to the present "population-based cancer control" organization, with a well-developed, stable platform for its service, education, and research mandate. The geographic centre approach, which involved the distribution of cancer care services according to population density and operated within a self-determined strategic plan governed by the regional health care agency, became the provincial cancer control program in 1974. The present provincial cancer control program addresses provincial needs with centralized planning, policy, and budget structuring, thereby implementing provincial policies through a coordinated regional cancer centre/community network system. In addition to the four regional centres, the cancer agency's control program oversees the communities' oncology network, which has a collaborative voluntary partnership with 19 community-based cancer centres; 6 community-based cancer services; and 10 consultative clinics across the province in conjunction with the chemotherapy and radiation programs. The community oncology network also supports appropriate delivery of cancer patient care and support in 30 community hospitals.

The cancer agency has adopted a provincial cancer control program, a population-based model, as its platform for providing cancer care services. This model serves the provincial population needs by focusing on cancer control rather than cancer treatment/care as its operating paradigm (Appendix H). This form of centralized planning and policy implementation enhances the delivery of care for patients, because it organizes care as well as the coordination and collaboration of the interdisciplinary team. The population-based provincial cancer control program serves the population by providing health promotion and maintenance programs to the "well" and "at risk" with direct or

indirect cancer-related treatments and care to persons with cancer through its regional cancer centres and community networks.

This form of providing province-wide cancer control programs with province-wide standards was initially established to ensure quality of care and equality of access. From discussions with nurses during participant observations, I noted that professional nurse and radiation therapist leaders' primary goal was to ensure quality of care at all times for all cancer patients, regardless of overcrowding in the clinics and minimal resource allocations. The cancer agency's strategic plan for the future acknowledges clinical space constraints and anticipates that issues with overcrowding will be offset with the new fifth regional centre, scheduled to open in 2008 (Appendix H). Over the past three decades, the provincial cancer agency has refined its organizational activities to provide the most effective and efficient cancer care possible for the people of the province.

The cancer agency's mission is "to reduce the incidence of cancer; to reduce the mortality rate of people with cancer; and to improve the quality of life for people living with cancer" (Appendix H). The principles of ethics embedded within the mission statement help maintain equity of services by providing for accessibility and quality care under the provincial guidelines for cancer management. Cancer services at the agency are guided by the agency's mission statement and provide population-based, outcomes-focused, and patient-centred care across the range of cancer control for the people of the province. The use of an evidence-based care approach is integrated into the clinical practice, thereby providing efficient and accountable care with respect to the measures of outcome and benefiting the population as a whole.

Cancer care research in the province is underpinned by the agency's cancer control activities' being extensively linked and integrated through regional cancer centres and community cancer centres and clinics, along with provincial networks. The cancer agency states, "Its principal business is to enhance the outcomes of cancer control" (Appendix H). Hence, the agency, with the provincial cancer control program as its platform, is a large organizational network comprising of corporate headquarters, regional centres, research centres, and networks supported by a common infrastructure that provides clinical services, research, and education as its benchmark. For example, as witnessed during the observational data collection, health professionals at the cancer agency, including chemotherapy nurses, were dedicated in implementing rigorous clinical steps outlined in the clinical trial protocols while providing patient-centred care at the regional centres. The nurses whom I shadowed indicated they valued the need for concurrent clinical trials within other regional centres, as this provided a more comprehensive coverage of the clinical trials and the possibility of a larger sample size.

### *Payment for Cancer Care Services in the Setting*

The cancer agency is funded for its cancer control programs by the Ministry of Health through the Provincial Health Services Authority with a mandate to provide an organized cancer control program for the people of the province. Resources for cancer care services are channelled through the agency's cancer control program; however, virtually all of the funding for cancer research is derived from the cancer foundation, private and public research grants, and non–Ministry of Health provincial and federal grants (Appendix H and I). I learned in discussions with the administrative office at the cancer agency during participant observations that allocation of provincial and federal

resources for the agency has been affected by changes in the health care reform. This has resulted in no incremental funding other than life support drugs since 2000 despite growth in cancer incidence and prevalence rates (Appendix H). Each regional centre makes a request for its yearly funding to the centralized budgetary committee of the cancer agency; however, recent budgetary restraints on health care have meant that all areas of the cancer control program compete within fixed funding.

The cancer agency is administered by an executive team comprising senior staff with leadership positions in the cancer agency. Each of the four centres has a leadership team that is responsible for that centre's cancer control program requirements, as per population demands. The leadership team represents each centre in the executive committee decisions for funding and resource allocations. In addition, there are provincial program teams made up of representatives of the programs from across the province and a provincial disease site/tumour group structure, which is a mechanism for establishing the content of the cancer agency's activities directed to the cancer control program. An interdisciplinary team extends across regional centers and is represented in the agency's executive committee regarding decisions on resource allocations.

Payment for individual cancer care services, including cancer-related treatments for the people of the province, falls under their federal/provincial universal medical services plan coverage. However, in some palliative and hospice care centres, there are additional costs for most pain and symptom-related medications. In addition, items such as wigs are considered to be over and above the general medical services plan coverage, and costs are usually borne by the patient or extended medical services plans, or else are donated by the Canadian Cancer Society when patients are on a limited budget.

This discussion for individual cancer care services now leads us into the context of the outpatient follow-up cancer treatment setting, where South Asian immigrant women experienced respect within health professional–client relationships.

### *Outpatient Follow-up Cancer Treatment Setting*

This study was conducted within two regional cancer centre settings located in a metropolitan city that served a large number of South Asian immigrant women population, among others. The population distribution in this metropolitan city included 46% Euro-Canadian, 18% East and West Asians who were born or whose parents were born in Asia, and 12% South Asians (Statistics Canada, 2005). The population in the region surrounding the metropolitan city is mainly Euro-Canadian, East and West Asian from China, Hong Kong, Korea, or Vietnam, South Asian from the Fiji Islands, India, Pakistan, or Sri Lanka, and Filipino, in descending order (Statistics Canada, 2005). The two regional centres involved in this study differ with respect to patient demographics because of the characteristics of the two community settings. Clinical Setting B served a slightly larger volume of South Asian immigrant women than Clinical Setting A because of the immediately surrounding community. The regional distribution of cancer statistics indicated Clinic B with the largest number of 5,485 new cancers, in comparison to Clinic A with the second largest number of 3,933 of all new cancers diagnosed in 2003 (Appendix H). The cancer agency does not keep statistics by ethnicity to indicate the volume of clients to an individual site; however, health professionals noted that a larger number of South Asian immigrants are visible in Clinic B than in Clinic A.

Although both of these regional centres fall under the same cancer agency jurisdictions, they differ in the scope and size of the interdisciplinary teams because of

the differing sizes and locatio two institutions. For example, Clinic A, which is centrally located around the and administrative centres, has a staff of more than 200 health professionals rang dentists to dermatologists, whereas Clinic B has a narrower scope in the interdisy team and provides mainly oncology care services, which include consultations, reatments, and follow-up visits for those who are going through the cancer journ interdisciplinary team at the outpatient follow-up cancer treatment clinic include al and radiation oncologists, radiation therapists, oncology, chemotherapy and r clinic nurses, dieticians, licensed practical nurses, counsellors, and unit clerks. A ne of the study, staff ethnic characteristics at both clinics consisted of male and f uro-Canadian, East and West Asian, South Asian, and Afro-American members terdisciplinary health care teams, in descending order. They ranged from 22 to rs of age, with 2 to 30 years of outpatient oncology experience. Both of the clinica gs had male and female South Asian health professionals on their interdisc y team; however, Clinic B, with the larger South Asian immigrant patient popul reflected a higher number of South Asian male and female medical and radiation ists, radiation therapists, and oncology and chemotherapy nurses.

Interpreters were book demand from a local independent agency that specialized in providing interp for legal documentations or medical translations. These South Asian male or fe terpreters served the cancer agency as well as other health care institutions. South patients were identified by name and were offered an interpreter at the time of the f ace clinical visit appointment. All of the initial consultations, follow-up appo ts for chemotherapy or radiation treatments, and

posttreatment consultations had an interpreter scheduled for translating important educational and decision-making information for the woman and her family members. Interpreters were not always scheduled during the chemotherapy or radiation treatments unless requested by the woman or her family members. Chemotherapy nurses voiced concerns about the competence of interpreters to understand and translate cancer-related information. Chemotherapy nurses felt that they, the nurses, lacked understanding of South Asian immigrant women's cultural behaviors, especially when the interpreters' tone of voice seemed a little harsh when they addressed women during clinical interactions.

South Asian health professionals who spoke either Hindi or Punjabi or both were able to communicate with their clients in women's own language. However, some health professionals spoke only Hindi or Punjabi or neither, depending on their age, gender, upbringing, background, or ethnicity. The cáncer agency's policy was to provide clients with the choice of professional interpreters rather than using family members as translators.

The availability of language-specific patient education material did not reflect the large South Asian immigrant population that the clinics served. The cancer agency had not expected the rapid demographic changes and had not been prepared to cope with the challenges of providing population-specific health care within the existing system. The subgroups within the South Asian immigrant women population further compounded these challenges of language and communication. For example, Hindi, Punjabi, Tamil, or Urdu was often the mother tongue for the women in the surrounding regions, depending on their country of origin. This diversity was visible in this study's sample, which

comprised South Asian immigrant women from the Fiji Islands, who spoke Hindi; those from India, who spoke Punjabi; women from Pakistan, who spoke Urdu and women from Sri Lanka who spoke Tamil as their first language. According to the nurse professional leader, the cancer agency is progressively addressing the issue of providing language-specific written educational material by working in partnership with interpreters of the various communities.

Health professionals, especially chemotherapy nurses, were concerned that critical written educational material in relation to serious side effects, for example, high fever due to neutropenia, constipation, diarrhoea, or fatigue, was not readily available for the South Asian immigrant population. According to the chemotherapy nurses, this lack of resources constantly put patients at risk and did not address the time constraints nurses are under when teaching patients about serious side effects, which become life threatening if left unaddressed. However, an analysis of the documents retrieved showed some language-specific material about cancer-related treatments available on the cancer agency's website that was not being used in clinical practice. The website information was not provided to women during their clinical visits either. Chemotherapy nurses in the clinics observed that time constraints, a lack of resources such as computers, and space availability made it impossible for nurses to inform themselves of current educational material to enhance their practice.

Each centre bases its approach to cancer care and treatment on the foundation of cancer agency standards, provincial programs with consistent and carefully designed care and support processes. This approach features teamwork and equality, and focuses on empowering patients as they progress through treatment, allowing the patient to

concentrate on getting well. Each centre has the opportunity to develop its own cancer prevention initiatives with a focus on cancer and a holistic spectrum of health. The centres stress psychosocial support for cancer patients, assist current psychosocial research, and help initiate new projects in this area in affiliation with the regional hospitals and universities. Although each centre serves a pivotal role in delivering the cancer agency's provincial cancer control strategies, its character reflects the community setting and area it serves regarding population demands, patient acuity, and cancer-related treatments.

Implementation of the provincial policy, guidelines, standards, and budget structuring, and resources for each centre is coordinated through the regional center/community network system within the centralized provincial cancer control program. The cancer agency has prepared these cancer management guidelines, standards, and health care policy guidelines based on the accumulated experiences of this agency, together with best practice evidence derived from major cancer centers throughout the world. Recommendations regarding policy guidelines and standards have been developed by tumour groups comprising oncologists, radiologists, pathologists, oncology nurses, pharmacists, and practitioners from health disciplines contributing to specialized oncology care at the agency in conjunction with the local university (Appendix H).

### *The Health Professional's Role in the Clinical Context*

Most of the nurses at the outpatient follow-up cancer agency clinics worked in collaboration with medical or radiation oncologists, who, in return, chose clients affected by a specific type of cancer, for example, brain tumours, breast or gynaecological cancer,

gastrointestinal (GI) cancer, or lung or prostate cancers. The main roles of oncology care nurses were to consult with clients, assess their physical and psychological needs, ease their symptoms and side effects by providing face-to-face teaching with written educational material, answer calls on phone-in help lines to provide support to clients and their families, and monitor the clients' condition during and after treatments. Most oncology care nurses indicated they were so busy that they often had to stagger their lunch breaks or, on some days, had no decent lunch times. The caseloads of oncology care nurses and other health professionals varied greatly, depending on their responsibilities. For example, oncology care nurses in the follow-up and patient review units saw between five and eight clients a day, depending on whether the clients were newly diagnosed, presently going through treatments, or coming for posttreatment visits.

The structure and the procedures of the outpatient follow-up clinical setting did not promote an interdisciplinary approach, excluding the oncology nurse from being present together with the oncologist during the client's visit. Health professionals felt that an interdisciplinary approach would have eliminated the repetition of information by both health professionals, thereby saving time, which the health professionals could easily spend elsewhere. In addition, health professionals shared that an interdisciplinary approach involving the medical oncologist and a female oncology care nurse would have reduced South Asian immigrant women's feelings of embarrassment and shyness. Oncology care nurses shared that an interdisciplinary approach would increase feelings of respect and comfort for women of any ethnicity when female health professionals provided cancer care.

Each chemotherapy nurse was responsible for six to eight clients in administering their chemotherapy treatment, which lasted from 1 to 8 hours depending on the specific cancer treatment protocol. Nurses in the chemotherapy clinic delivered chemotherapy drugs ordered by medical oncologists as per treatment protocols. According to the chemotherapy nurses I shadowed, nurses constantly double and triple-checked their orders when processing any of the chemotherapy treatments, because there were so many things that could go wrong, especially when clients were on clinical research trials. According to these nurses, chemotherapy nursing is probably the most stressful in oncology care nursing because of the technical skills required, along with the psychological impact of constantly being aware that each client is receiving the right type and dose of medication, and having to check their blood results prior to cancer treatment drug delivery. Most chemotherapy nurses indicated they still felt a little rushed when they left work and had to slow their mental state down on their way home.

The medical oncologists whom I shadowed discussed treatment plans with clients and took time to explain new chemotherapy drug treatment protocols and their side effects for the women's type of cancer. According to the medical oncologist, teaching a client about any cancer-related treatment was complex, especially when protocols and procedures changed constantly because of research results from clinical trials, discontinued drugs, and agency policies and procedures. They had to keep abreast of the changes and constantly educate themselves about these changes before they could make recommendations to clients.

The radiation therapists worked in collaboration with the radiation oncologists to develop and map out clients' treatment plans. In addition, radiation therapists provided

teaching for easing the symptoms and side effects of radiation, assessed clients' physical and psychological needs, and monitored their condition during ongoing treatments. Radiation therapists referred complex skin reactions or side effects of treatments to the nurse-managed radiation support clinics. In general, a client might have anywhere from 5 to 30 daily radiation treatment visits depending on the site and type of cancer. Radiation therapists stated that clients could sometimes experience long waiting periods because of mechanical problems with the radiation treatment machines. According to the administrator, there is a shortage of nurses and radiation therapists experienced in the cancer agency protocol at both radiation and chemotherapy clinics.

Each discipline scheduled team meetings to discuss issues that arose out of their practice, such as shortage of space and overcrowding; the need for new instruments or machines; new drug procedures, protocols, and guidelines; or a particular patient who needed focused attention. Health professionals in outpatient follow-up cancer treatment clinics do not always have an interdisciplinary team meeting for all patients unless there is a need for extensive counselling during treatments or when a recommendation is made to the palliative care team. At this point, the social worker or the palliative care team will be consulted and the patient will be referred to the appropriate health care team. To illustrate how the interdisciplinary team coordinated care for a patient, I will present a composite case of a South Asian immigrant woman's typical journey through the agency.

*Journey of a South Asian Immigrant Woman Going through Cancer Treatment*

A 54-year-old woman is seen by her family physician for the lump on her left breast. The family physician sends her for a mammogram and performs a needle biopsy. After receiving the results of the mammogram and the biopsy, the family physician sends

her to the surgeon. The surgeon consults with the woman and advices her about the need for a lumpectomy, mastectomy, or reconstructive breast surgery. She might not have a choice of which surgery is performed because of the extent and size of the tumour. The surgeon makes this decision at the time of the surgery, and the tumour is sent to the cancer agency lab for pathology.

The surgeon refers the woman for her initial consultation at the cancer agency, if the tumour is found to be malignant, approximately 4 to 6 weeks postsurgery. Usually, the surgeon informs the woman about the pathology results and malignancy in person. However, the health professional sometimes communicates this information to her over the telephone. Generally, the surgeon provides the woman with an educational package, which includes educational reading material about breast cancer, the pathway that she might go through with her cancer, the possible choices of cancer treatment, and information regarding counselling services at the cancer agency. This information is mostly in English. The woman receives a telephone call from the cancer agency outpatient follow-up unit clerk, who schedules the appointment and offers an interpreter, if needed. During the first visit to the cancer agency, a volunteer guides the woman to the appropriate unit, where she reports to the unit clerk. The oncology nurse then takes the woman into an examining room, verifies the health care information, and gives her information related to counselling services at the cancer agency, the clinic's procedures, any financial issues related to medical expense while going through the treatments, and the contact person for complications in relation to side effects from the cancer treatments. The nurse gives the woman the telephone numbers for the phone-in support service to contact a nurse during standard business hours. The nurse also answers any questions

related to the cancer diagnosis or pain and symptom management for the woman and her family. The oncologist, together with the interpreter, discusses the cancer diagnosis; the treatment plan, including options for either or both chemotherapy and radiation; and the prognosis. At this time, the woman can make the decision right away or take a few days and discuss these options with her family before choosing which treatments to have. The oncology nurse checks the oncologist's notes, follows up on any other related information for the woman, and answers any question the woman has before discharging her.

The next visit for the woman will be at either the chemotherapy or the radiation clinic, depending on the cancer site and stage. The initial visit at both the chemotherapy and radiation treatment clinics will involve a one-on-one educational session with the oncology nurse or the radiation therapist, along with a visit to the physical set-up of the radiation and chemotherapy clinics. The woman's next visit will be for the actual chemotherapy or radiation treatment. She will have ongoing check-in points with the medical or radiation oncologist and oncology nurse throughout the chemotherapy or radiation treatments. At this point, the health professional answers any questions or issues that have arisen from the treatments. The woman or her family members also have an opportunity to telephone the support help line or drop in at the radiation support clinic for any emergencies, issues, or complications that arise from the cancer-related treatments. A social worker may be consulted for further counselling at any time during the cancer journey if the need arises. The oncologist, chemotherapy nurse, radiation therapist, and oncology nurse as an interdisciplinary team might have to discuss this woman's cancer treatment plan if the family or woman are having unforeseen complications or the woman

has become palliative during the treatments. The woman will be scheduled for a 3-month, 6-month, or 1-year check-up after completing the treatment, unless there are unforeseen complications. After this, she is discharged from the cancer agency to the family physician. This examination and lens into the clinical context of the setting leads us to the personal context of South Asian immigrant women's experiences and expectations of respect.

## The Personal Context of South Asian Immigrant Women's Experiences and Expectations of Respect

Before we can understand South Asian immigrant women's experiences of respect within health professional–client relationships, it is important to describe the personal context of their experiences and expectations. Important dimensions of this context are described in relation to women's understanding of the cancer journey, the challenge of expressing themselves in the relationship with health care professionals, and their previous health care experiences.

### *Women's Understanding of the Cancer Journey*

Women's stories from the beginning of their cancer journey allowed me to see the importance they put on detailing the account. The significance placed on the presence and support of family members and various meanings ascribed to cancer and its related treatments came through in the accounts. Most of the time, the women shared details of cancer by discussing the surgery, and their understanding of the stages and types of cancer and its related treatments. This understanding of their cancer condition seemed important for women, as described by these women's stories of their cancer journeys:

I had only been in Canada for three years when I first found out about the cancer. Well in the beginning it is very scary and I was really scared and I thought I'm going to die of this horrible disease. I believe it's mostly because of the media. They show it as a very horrible untreatable disease that you are going to die of soon. And I was relatively scared of this, but then after when I went to the cancer agency, and I talked to the person in charge and they gave me books and things to read. After a while, I realized that it's not any worse than many other diseases; for example they told me that it may not be curable, but it is treatable. You can learn how to deal with it, because it is not any worse than any other disease. (A mother with young children, Muslim)

In September, the pain had become unbearable and I went to see the doctor. When he told me what it was, that it was cancer, I was in a lot of depression, I was very depressed. I was very depressed at this time. The counsellors at the hospital, they helped me a lot. I am here but some of my children and grandchildren are back in my country. I do not have a husband and I have been here for three years. My family members helped me a lot. (A widow with grandchildren, Hindu)

The interviews provided insight into how women's immigration and transition experiences, along with the fact that their extended family members might be overseas, were all integrated into the stories of their cancer journey. It helped me to see their understanding of the cancer condition process and demonstrated their grasp of what is still to come in their journey through cancer. In addition, these experiences helped

identify how women experienced respect within health professional–client relationships in light of their understanding of the cancer condition process.

Women generally felt that cancer was a horrible disease that took over people's lives. Some women felt that suffering and enduring pain is part of a human being's journey, and this journey of going through cancer is something they must do, as this woman shares her story of suffering:

> Since I came here I've had operations on both of my eyes and I have suffered from these at that time. You know as a human being I have suffered, so we all have to suffer as human beings. The suffering with cancer is part of the life for me. We have to suffer because suffering is part of a human being's life. They attend to me and respect me. It is that they are worried about me, they care about me and they attend to me I am a patient over there, and they look after me by paying me regard and are attending to me. (A mother whose children are in Canada and her home country, Hindu)

Some women believed that suffering and pain are things that every human being goes through. In light of this belief, most women felt respected by the care that was provided by health professionals in this clinical setting. Most women were pleasantly surprised by the respectful care they had received at this clinical setting; however, they felt challenged because of their language and limited English language skills.

*Challenges of Expressing Self in Relationships with Health Professionals*

Because some women did not have an opportunity to speak English regularly, they had difficulty expressing themselves in relation to their health care experiences. They found this to be a challenge in their everyday lives as well as in the health care

system. These challenges sometimes coloured the women's ability to ask questions or express their suffering while journeying through cancer. As well, some women felt frustrated when they were unable to express themselves in this context, although they normally spoke and understood English:

> I couldn't express myself clearly and I wasn't sure that I understood the answer as well. There wouldn't be a difference between the Canadian woman and the immigrant women. Only thing is the language, we don't have the ability to express ourselves as the Canadian woman can, you know it is little bit difficult and it is a challenge. My mother tongue, in my language it is easier for me to express myself when I want to talk about my feelings and to earn people's respect, it is very easy for me. (A mother with young children, Muslim)

This feeling of frustration was not because of women's inability to speak the English language but because they could not find the right words, phrase, or terms to describe what they were feeling. This marginalized them during their interactions, because they were unable to speak from their heart about their suffering and pain related to the cancer condition. For women, the ability to express the self was important, especially when discussing a life-threatening illness that affected their femininity and gender self-perception. Furthermore, as mentioned previously, the absence of an interdisciplinary approach meant that information might be repeated but also that the women could not be assured of having a female clinician present during physical examinations.

Some women shared that at times they did not want to use English because the suffering and pain took up so much of their precious energy, which they needed to

perform the activities of daily living. This woman shared that it was an effort to remember how to use English during times of suffering:

> Usually I understand English but when there is a lot of pain involved then I don't want to speak in English at all. I just don't want to speak or I do not want to think so much. If they speak to me slowly in English I understand them. (A widow with grandchildren in her home country, Hindu)

The outpatient follow-up clinical setting mainly provided written educational material in English, which excluded this South Asian immigrant woman, as English was not her first language and she had difficulty retaining the information because of her cancer condition. This woman's story indicated that written educational material in her own language that she could take home would have facilitated her understanding of the pain along with providing explanations on how to deal with cancer-related pain before it became unbearable. She felt that these materials would have reinforced the information provided during her clinical visit at the outpatient follow-up clinic.

Challenges in expressing themselves were also heightened for some South Asian immigrant women during their transition period because they had to learn the language and find suitable employment to support themselves in the new country. Experiences of respect within the health professional–client relationships were coloured by women's previous experiences during their immigration and transition period, when they felt helpless and diminished because of their inability to express themselves in English. This was especially the case if women had been in Canada for only a short time before their cancer diagnosis:

vas difficult because I did not know much about
Well the first thing is
n gradually I learned and it became better and I grew
Canada and the custor
ne, it felt a little difficult because we had to get jobs
from all this. When I
ficult because we did not know the language. They
you know and it was
eriences, which we did not have. How can we get
asked for [the] Canad
working here? Then we got jobs that were good, but
Canadian experience
nd it was not like in our own country where we know
we had to start somev
one. (Widowed with children and grandchildren
more about how thing
overseas, Christian)

required that professional interpreters be made
The cancer agency's
clients. Generally, women were identified by
available for non–English-sp
n interpreter for their clinical visit. Women and their
surname and asked if they ne
English were provided with an interpreter during their
family members who did not
articipant:
clinical visits, as described b
are interpreters there. Only sometimes there isn't
Well most of the time
in law is there, but most of the time I understood
an interpreter and my
peak it, but I understand them and at this time I have
them. I may not be ab
A widow with grandchildren, Hindu)
to speak to them in H
onals who were part of the interdisciplinary team and
South Asian health pr
ural behaviours and beliefs were an asset to the cancer
had some understanding of t
and familiarity for South Asian immigrant women
agency, because they brough
niliar clinical environment, especially when they could
who felt uncomfortable in an
ally beneficial when health professionals spoke
not speak English. This was

various dialects of the South Asian women's languages. Health professionals of South Asian descent added to the diversity of the staff characteristics, especially as Clinical Setting B provided cancer care to a large South Asian population. Having someone from their community allowed women to feel respected, especially when South Asian health professionals spoke their language and conversed with them while they provided care:

> Well in my case, I do not speak English, sometimes if I understand something then I would reply, otherwise I do not understand them. When I meet those who speak my language, then I speak Punjabi to them and they are very happy to speak to. You know some nurses only speak Hindi. When they do the machine, they talk to me and sometimes it just happens that they are from my own town in India. I may not speak English but I feel happy when they have a smile on their face and even the white nurses call me BiBi and say hello to me in my language. (A mother with married children, Sikh)

Most women described feelings of being respected within the health professional–client relationship regardless of whether they spoke English. These challenges of expressing themselves hindered communication within health professional–client relationships. South Asian immigrant women's previous negative or positive health care experiences influenced their experiences of respect or lack of respect at the outpatient follow-up clinical setting.

### *Previous Health Care Experiences*

Previous health care experiences encompassed women's perceptions of their relationships with health care providers, their exposure to the health care system, and the roles expected of them as the "patient." Although most women had lived in Canada for

many years, they often had restricted health care visits to their family physician to obtain treatment for specific health problems (e.g., pain, flu, or other minor health problems). Some women had never been hospitalized before in any country and so had no personal experiences in that regard. One 69-year-old woman, who had immigrated to Canada 14 years earlier, described her surprise at finding out that she had cancer, especially when she had considered herself to be in good health:

> I am by myself here since my husband passed away and that is why I stay with my relatives. I might move back to be with my children. No, no. Never for a moment did I ever think that I would get cancer. It has shaken me up, because I was always very healthy, I did not even get the flu. (Widowed and retired with grandchildren in Canada and overseas, Christian)

The health care practices of most South Asian immigrant women were influenced by their past health care experiences in their previous or new country of residence. Women who were still in the transition period were influenced by their previous health care experiences in their country of origin in comparison to the health care system in the new country. These included their choices as a patient, their role when making decisions about their treatments, the health professional's ethical role and responsibility in providing explanations to the patient rather than the family member, and learning the structure of the health care system. A 40-year-old woman, who was a recent immigrant, had difficulty grasping this "new method," in the beginning, especially when she had to make a choice between chemotherapy and radiation or only radiation:

> I needed some data to make the decision myself, especially in the case of chemotherapy. The doctor gave me the option. He did not say a hundred percent

> that you have to do the chemotherapy. This was a little confusing for me because I am not used to this attitude from the doctors, they should make the decisions for you. You know back home they don't give you an option…and they talk very confidently; that this is very good for you and this is your medicine, you have to do it, so you feel that you have to do it, but I feel that in Canada they act more differently, they just give you the choice, and say ok, this is your option, this is the chemotherapy, there are some benefits, there are some risks involved and this is your decision, and even they offer you to go and have a second opinion. I am not saying this was bad, but it was a little difficult because I'm not a doctor and I don't know exactly what the better choice is for me. Their method is different too, here I mean the doctors, I found them very honest and I don't think honest is a good word, very strict and very straightforward, they tell straight away in the first session, you know in the first meeting. But back home they normally they usually talk it over with the family members especially with serious illness. (A mother with young children, Muslim)

Women understood that these differences are not necessarily good or bad, just different ways of providing health care that were unique to the Canadian health care system. However, these differences in the health professional roles between the two countries created underlying complexities when women experienced and described respect. They understood that this way of providing health care was different but not necessarily disrespectful.

Women brought their own perspective, which they used as the lens for their experience of respect within their health professional–client relationship. Their

perspective or their relational experiences from other health care encounters in their country of origin or in this new country had an impact on how they experienced respect within the health professional–client relationship at the outpatient follow-up clinic. Some of the women's previous health care experiences in their country of origin had left them feeling neglected and "brushed off" by their health care providers. They stated that nurses in their country of origin had not been respectful or caring during their hospital stay. They felt that being in this country had saved their lives; they would definitely have died in their country because of neglect and a lack of expertise and technology. This woman described her previous health care experience from her country of origin:

> They don't care as much for patients over there as they do over here. The patient is left alone a lot of times because there is a shortage of staff and the nurses and doctors, but over here it is very good. Over here they talk to you nicely and politely and they are kind and they don't yell at you like they do in my country. Also my experience in my country is that you can go to the clinic or the dispensary all day from the morning till one and you still won't see anybody for a long time. I know that if I had been in my country, I wouldn't have been able to be saved. (A grandmother, Hindu)

South Asian immigrant women indicated that health professionals at the cancer agency setting brought "their" own perspective to the health care relationship, which influenced their relational work experiences in "this" particular health care institution. One woman described her experience of being brushed off by a health professional during her emergency room visit, when the health professional did not take the time to provide clear explanations about her condition:

> I mean previously I have been to the emergency and you know sometimes it happens I broke my ankle one time and they are not so friendly I mean they are okay, but you know maybe because they are in a hospital and too many people in and out you don't get that kind of attention. (A retired mother, Muslim)

Some women suggested that health professionals sometimes stereotype South Asian immigrant women, assuming that most do not speak English and know little about their health care. This participant described her frustration when she went for her day surgery appointment to a hospital setting and was sent home without the procedure's being performed:

> Yeah, but if they don't respect me for being there I will stand there and scream. If they order something for me and then they turn around and don't do it, I will stand there and scream. This is not the first time this is happening. Sometimes we have to make a scene in order to get through, regardless of whether they think I am an idiot, because it is not easy to be the patient. (Retired mother who spoke only Hindi, Hindu)

Previous health care experiences provided insight into why some South Asian immigrant women felt surprised and valued their positive cancer agency clinical experiences within health professional–client relationships. In light of some women's negative health care experiences, most women did not come with an expectation of respect in relation to health care at the cancer agency.

Some participants suggested that health professionals play a very important and powerful role in many South Asian immigrant women's lives. This is because of the respect that women have for physicians and nurses who provide health care, especially in

terms of cancer conditions. A few women indicated that doctors and nurses were "healers," as voiced by this participant:

> Yes they are like God who looks after us and God is our parent. That is doctors and nurses are like God because they look after us. We all want God to look after us and keep us healthy, it is our fate. In my opinion the doctors and nurses are just like God as well, they are very similar to what God is, because they save lives and they take care of people when they are ill. God listens to us as well and they are all part of the same God, I mean the doctors and nurses are part of God as well and they listen to us, to our stories. Let me put it this way, I have never had a better relationship with the doctors or the nurses as I have at the cancer agency. (Retired with grandchildren, Hindu)

Spirituality and fatalism went hand in hand for some of the women because of the high value they placed on doctors' advice and their strong belief in God. A mixture of a few older and younger women voiced such beliefs. This seemed to form a contextual part of these women's previous health care experiences. Both for participants who were English speaking and for those who were non-English speaking, it seemed important that although they believed that God and their own fate might play a part in their cancer conditions, their belief in God alone would not get them through the cancer condition. Women related their personal belief in fatalism and God to the importance they placed on their relationships with health professionals. Some women felt nurtured by health professionals who were attentive and listened to their stories unconditionally while caring for them during their clinical visits.

These dimensions of the personal context of South Asian immigrant women's experiences were used as the starting point for women to begin their stories of respect within health professional–client relationships. In light of South Asian immigrant women's personal contextual experiences, it was crucial to consider contextual factors such as gender, social environment, culture, and structuring of the health care system and the clinical setting, which influenced how most South Asian immigrant women located themselves in light of their perspective within the health professional–client relationship. I will now describe women's perceptions of the health professional's approach to the relationship in the clinical setting.

## South Asian Immigrant Women's Perceptions of the Health Professional's Approach in the Clinical Context of the Setting

Participants consistently responded with the same South Asian term for respect (*ijjat*) and related its meaning to their experiences within health professional–client relationships. This helped me to determine whether the participants and I were discussing the same concept. In this section, I have presented the findings as characteristics of respect that South Asian immigrant women experienced from their perceptions of the health professional's approach. Excerpts from the women's stories accompany the characteristics to help illustrate women's experiences and a perception of the health professional's approach.

To capture a more complete picture of South Asian immigrant women's experiences and expectations of respect, I have created a pathway that follows women's perceptions of the health professional's approach as they entered the health care relationship. South Asian immigrant women described health professionals' ways of

being, including their professional behaviour and courteous manner, being acknowledged as a fellow human being and being greeted, health professional's way of talking to women, and attending to the person as part the health professional's approach, which created respect within the health professional–client relationship.

### *Health Professional's Personal "Way of Being"*

Although health professionals' personal "way of being" was characterized as an individual health professional's perspective, it was more adequately conceptualized as being strongly connected to the social relations of being in relationships where they were formed, especially the social context of the outpatient follow-up clinical setting at the cancer agency. South Asian immigrant women described that an individual's personal way of being was seemingly placed in the broader societal context, because personal manifestations of beliefs, values, expectations, and way of being were related to cultural and societal structures. Personal way of being was played out in the social context of this outpatient follow-up clinical setting when both health professionals and women brought their individual perspectives to the health professional–client relationship.

The women's perspective included their cultural beliefs about their cancer conditions viewed through their South Asian ethnic lens, their age, and their upbringing in their own country, which had blended with the Western culture in the new country. On the other hand, health professionals had their personal beliefs and values, which provided the lens for the development of the professional practice. Women described that the health professionals' approach was inclusive of their individual make-up, indicating their personal perspective, which included professional behaviour indicative of their knowledge and their professional lens. In addition, women shared that the health

professionals' courtesy and manner were part of their personal perspective, which crossed over into their professional approach.

Findings suggested that South Asian immigrant women felt that respect was bestowed through the health professional's approach, or way of being within the health professional–client relationship. According to women, health professionals' way of being included their ways of interacting with women, their ways of explaining and providing information, and their approach to the health professional–client relationship. For example, some women described feeling that the health professional was their partner in the journey through cancer. Respect was expressed in the relationship when health professionals provided detailed explanations about their cancer condition:

> They don't only pay respect in attitude; it is also their way of being. Yes their way of being is the way that they respected me, the way they talked and the way that they answered my questions and the information they gave me. I would say it was their way of being, who they are, the whole attitude, the way they talk, and the way they answer the questions. I really [wanted] to know what was going on. I want to know about everything, for example, what is this medicine, what are the side effects; what is the worst case; what is the best case; and they always knew how to answer the questions. It was very good. (A mother with young children, Muslim)

The cancer agency's policy guideline in relation to patient-centred care when providing cancer care was being practiced by health professionals at the outpatient follow-up clinic, as evidenced by South Asian immigrant women's stories. South Asian immigrant women's stories of health professionals' respectful interactions with them

indicated that these professionals were aware of their actions when providing cancer care for women:

> They were soooo very nice. It was the same with the radiation therapists, doctors, and nurses. They were very nice. So with this kind of cancer, their way and their confidence I think that helps a lot. I looked forward to going there everyday because they were so nice. (A widow with her children and grandchildren overseas, Christian)

The clinical setting had structural limitations, such as time constraints, schedules, and overcrowded spaces, that inhibited the development of health professional–client relationships. However, according to South Asian immigrant women, most health professionals were still able to create respect within health professional–client relationships. This woman illustrated her perception of respect and the differences in health professionals' personal ways of being and their approach to the health professional–client relationship:

> I think it is the way that they are brought up, their beliefs, and their values towards other people. The way they think of the other person and their ways toward their client shows this, especially when they greet you by shaking your hand or not when they come into the room. For example, as I said before there are two doctors that I dealt with at the cancer agency; one for chemotherapy and one for radiation. The one for chemotherapy got up, shook my hand, greeted me, asked me how I was, and smiled at me. This made me comfortable and I was ready to listen to what he had to say. He even made sure that I understood everything before he left and asked me whether I understood at least three times

> before he left. On the other hand, the other doctor from radiation just walked in and asked me if I had any problems that I wanted to discuss and if things were all right with me. He called me by my surname to confirm that it was I and then proceeded to tell me what was going to come next in the treatment plan. This was his way of being or dealing with his clients. The difference is their background and upbringing. (A retired mother, Muslim)

Some women also described "subtleness" as an individual's way of being within the health professional–client relationship. This subtleness of the individual was perceived as respect or not and was determined by the health professional's appearance, behaviour, or actions at the beginning of the relationship, thereby setting the tone for the relationship. In addition, some women felt that a health professional's way of being in the relationship indicated respect or not for the "client," who was a "human being" with emotions. The "open approach" to the relationship made most women feel more comfortable, as voiced by these two participants, who described similar versions of this notion:

> I would think that the subtleness is their way of being, you want to be kind to the people, be nice, be open so that the patient will feel comfortable, doesn't feel that she or he is in a very bad or unusual situation. On the other hand, the patient feels that his [her] health problem is taken seriously, you know what I mean. If they are very, how to explain, when I heard [about] my illness, I feel I just want to be comfortable when I see that they attend to me and they are open. If I feel that they are very busy and they don't have time then I don't feel comfortable. I want to see a happy face and they attend to me and I want to see someone that is helping me

> and trying to help me. What else, hmmm and on the other hand, I want and I need to feel that they are serious and they are attentive and I need both of these, I need them. (A mother with young children, Muslim)
>
> You know just the appearance of the person, just two different things, that is something in the appearance and there is another respect that is inside you, maybe some people talk very nice, you know laugh and are very nice and in the end they do whatever they want to do, or maybe sometimes it is the opposite. Some people they don't seem very nice, but inside they are very good. Therefore, the way that you talk to people, the way that you talk to others, this is the first way of respect and then after a while the action is very important, but in the first place impression is important. (A widow with grandchildren in Canada and her home country, Christian)

Most women described feelings of being respected or not by health professionals' way of being and demeanour during their first meeting in the relationship. There are two parts to this relationship: (a) the South Asian immigrant woman and (b) the health professional. Both the woman and the health professional brought their underlying assumptions, indicating their beliefs, and way of being to the health care relationship. This relational experience manifested respect or not in the social setting of the outpatient follow-up clinic, depending on the individuals' way of being when they first met the other. Professional behaviour was part of the health professional's approach that indicated respect or lack of it, especially when health professionals took time to provide explanations despite their busy schedules. Women felt respected when they were given

explanations from health professionals who showed professional behaviour and were courteous in their manner toward the "other" person in the health care relationship.

*Courteous Manner*

Health professionals' way of being, courteous manner, and professional behaviour were intricately interwoven within the meaning of respect for South Asian immigrant women. For most participants, this approach to the health professional–client relationship indicated that health professionals regarded courtesy and professional behaviour as part of their ways of being or their makeup as health professionals who were in relation with women in the health care relationship. A positive, courteous manner was deemed a part of the social standards of relational exchange between health professionals and South Asian immigrant women. It was important for women that the health professional be respectful of them by having a "nice manner" when providing explanations:

> I didn't know what to ask and I didn't know what I should expect. They told me and explained everything to me in a very nice manner and a good way and behaviour. Their behaviour and manner was good when they talked to me about what I would expect with my illness. This made me feel good. It would not make me feel good if their behaviour and manner was not good. The therapist's behaviour was good and [she] made me feel respected. (A widow with grandchildren, Hindu)

South Asian immigrant women felt that health professionals showed them courtesy and consideration for their cancer condition when they invited them to sit and to be comfortable before beginning the conversation. For most women, this behaviour showed politeness and respect, which formed part of the broader context of social

conduct within health professional–client relationships in the clinical setting. Most women felt this to be a small part of the larger picture that led toward being respected. This woman who was over 60 years of age described her experiences with a South Asian female oncologist:

> Well for example when the doctor sees me she sits me down on the bed and then she examines me and she speaks to me in Hindi and she knows I don't speak English, so she speaks to me in Hindi. She told me that I don't have any other problems, the pneumonia is now gone so I'm doing better with the tests. You know how we are used to sitting on the chair, but instead of sitting on the chair she sat me down on the bed and she examined me in the front and the back and she checked me out. (A grandmother with children who reside in her home country, Hindu)

The distribution of South Asian health professionals in the outpatient follow-up clinical setting, especially female health professionals, provided familiarity with South Asian immigrant women's cultural behaviours, language, and their perceptions of gender roles and identity. This added to the development of respectful and nurturing health care relationships that valued South Asian immigrant women's need to share stories of their cancer condition in their own language without the presence of an interpreter.

Most women described that the structure of the clinical setting, the volunteers, and most health professionals' way of being made them feel comfortable and at ease. This was felt especially by some of the older participants, who felt happy to be recognized by the health professional who had just examined them, especially when they were in an unfamiliar environment. This indicated respect for them as "people with

emotions" rather than just clients who were seen at the clinic as part of "the health professional's job":

> She's very good, whenever she sees us she always takes the time to say hello. You know not everybody has the time for us all the time but she always does. It makes me feel very good inside, very happy because I feel special and it makes the door open for me to tell them if I am feeling any pain or anything. I am able to talk to them more openly. It is sort of like she's a friend. (A mother with married children, Sikh)

Being asked about their well-being by health professionals was experienced as respect, especially when these exchanges were generally beyond the reaches of routine clinical interactions. These exchanges made women feel comfortable and more at ease, especially in the foreign environment of the clinical setting. Providing courtesy through recognition was not similar to being greeted but part of building healing health professional–client relationships that manifested respect and led to positive outcomes for the women and their families. It provided a respectful environment in which to be treated, giving them encouragement to come back for the treatments, as recalled by this woman, who came in for daily radiation treatments for thirty-five days:

> Yes, they call you by your first name and always say "hello, how are you?", and they ask "how was your weekend?", that kind of thing. And they would, say "have a good weekend," if it happens to be a Friday. And I felt that they were my friends. The men as well, but mostly they are ladies, but the men are nice too, they are very nice. They were so friendly with me, you feel like you have known them for several years, you know. It is hard to imagine that there are people like that,

> they are so nice and make you feel special and you think they are family. If they were not talking and were not entertaining then it would be hard, but they talk like this with respect. They put you at ease and you feel better already. I think they are doing a very great job, you know. I looked forward to going there everyday because they were so nice. (A widow with grandchildren, Christian)

Most South Asian immigrant women experienced health professionals' open and friendly approach and their way of being in the relationship as being respectful. The notion of human courtesy and friendship favourably directed toward women was counted as respect, as voiced by this participant:

> I would say courtesy and friendship is all part of respect. A person's ways and their manner within the relationship and the openness of the person with friends or other people is what I call respect. (A retired grandmother, Sikh)

Most South Asian immigrant women described health professionals' way of being; this included their professional behaviour and courteous manner, as respect. These characteristics of respect were deemed to be part of the social exchange, thereby providing comfort and safety.

*Professional Behaviour*

Women's descriptions of "professional behaviour" included health professionals' providing detailed explanations about the illness, its related treatments, and side effects in a friendly manner. This allowed women to feel respected, especially when health professionals took time to share their knowledge about cancer and its related treatments. Women shared that they needed this information to make decisions about their cancer condition, its treatments, and side effects. This woman described feeling satisfied and

comfortable with the physician's professional behaviour and role when providing explanations about her cancer condition:

> I feel that I don't have to try hard to learn something. I feel that everything is ready for me and you feel comfortable in this situation, sometimes you feel you have to fight for your rights and for everything. Even though I did not know many things, even then I did not have to fight for anything. They had everything for me already. It is that I believe they are doing their job in the best way, because they care about their job. I am part of their job and it is important for them to consider my opinion, my comfort. I think it is respecting to the patient when you have tried to do your best. If you do your job you are caring about that person willingly. It is the same thing in health care, in clinical, I am part of their job, and their job is serving me as a patient. It shows that they are thinking about their action. You know, it means that they are caring about me, and it is respect. (A grandmother, Sikh)

Some women hoped that professional behaviour would override health professionals' negative way of being, because an unfriendly approach could be perceived as disrespectful. Respectful professional behaviour was apparent not only in their way of being when health professionals approached women but also in their actions when they conducted themselves as "professionals" in the health care relationship. It would seem that the chemotherapy clinic's overcrowded setting, together with health professionals' having to provide very precise and efficient care, could hinder respect within health professional–client relationships. This woman illustrated how a health professional's way of being and actions manifested themselves as professional behaviour:

> Especially in this situation you know with my illness, we don't only pay respect in way of being or friendship, but in action as well. Well I was thinking, which one I would rather have; a nice happy doctor who is just careless or someone with a bad attitude or who is unfriendly, but who is professional and someone that I am sure knows what to do, someone professional. I definitely would choose the second. (A retired mother, Muslim)

Health professionals' positive ways of being and their professional behaviour instilled confidence in South Asian immigrant women, especially when they felt fear about having cancer or undergoing the related treatments. Some women gained the confidence they needed to deal with cancer and its related treatments when health professionals provided explanations in a respectful manner:

> There is also the other side of respect when doctors are so confident and the way they come, you know their way of being and especially when I had to get a different kind of treatment on the other side, they were informative and explained everything nicely and did so much for me. Well just that they gave me all the information that I needed and told me to go home and think about all the information and the treatments and then come and tell me what you want to do. They told me to make a decision with my family members and then come back to the cancer agency. (A retired mother, Hindu)

Most women felt respected by health professionals' positive and friendly approach but realized that health professionals do not have to drown in the client's suffering. Health professionals needed to maintain an objective, "professional" way of being between the client and them to survive the emotional intensity of their work.

Women shared that health professionals must constantly battle this issue, especially when providing cancer care services for those who are young with families. This younger woman highlights the need for health professionals to take care of themselves while being respectful within the relationship:

> I don't know, I really think the nurse or the doctors or somebody who is dealing with patients in a life or death situation with someone who is young, cannot be involved emotionally with every patient. They can't survive the worrying all the time. All I expect are the facts and care, but they need to survive on their job. The only thing that I want is respect and attention. I don't expect that they cry for me, no, I don't want that, I just want they do their job or maybe they need a free mind because not everybody can do their job professionally, you know. (A mother with married children, Sikh)

Health professional–client relationships took place in a clinical setting that had social expectations because of the relational nature of interactions. Both parties going into this social relationship had expectations of being treated with courtesy and manners, which are inherent qualities of any human-to-human relationship regardless of culture. The patient-centred approach in the cancer agency's policy guidelines had an embedded influence on how health professional–client relationships were developed. Most women described feelings of being treated as partners in the relationship rather than feeling powerless, because they were the recipients of knowledge provided by the health professional. Although health professionals' way of being was one of the characteristics that indicated respect or not for women, however, it is important to recognize that it was a

small part of the whole experience of being acknowledged as a South Asian immigrant woman who is journeying through cancer.

*Being Acknowledged as a Fellow Human Being*

Most women described that the feeling of being acknowledged as a human being was one of the key characteristics of respect within health professional–client relationships. For most, this indicated that health professionals recognized their existence as "human beings, as women" who were more than just clients with a type of cancer. The women felt generally accepted and worthy as human beings with their personal experiences when health professionals made genuine attempts to convey respect while providing care and gave detailed explanations about cancer and its related treatments. This woman shared that some health professionals went beyond the call of duty by treating them as friends rather than only as patients:

> I am a patient over there, and they look after me so well with respect. I feel like they are my friends and I'm their friend. I feel a real friendship with them and they feel like friends. They hold onto my hand and they rub my hand and then they will do a prayer before the injection before the needle. [Woman is rubbing her hand over her hand imitating the action.] Like a human being, I was cared for like a human being. They were very good over there. I really admire them every day when I go there. I have been there three times already and this is my fourth time, oh no this is my fifth time, one more time to go. (A widow with her children in her home country, Hindu)

This woman recognized that the health professionals' open approach allowed her to see the woman as a human being who shared in her humanity, which was directed toward the

vulnerable human being with emotions rather than only the patient. For South Asian immigrant women, being acknowledged typically involved recognition that the health professional's clinical gaze extended beyond the particular health care role or task within the clinic.

Fears of being in the "patient role" were alleviated as some women felt their expectations of respect being granted during their relational experiences with health professionals who acknowledged their basic human emotions. These women described their experiences and perceptions of being acknowledged as people, rather than as patients, when they were "guests" in the clinical setting. Women felt that health professionals respected their fears. The treatments were foreign for women, especially when they could not communicate with the health professionals during the treatments, which often lasted 3 to 8 hours. The outpatient follow-up clinic did not always arrange for an interpreter for women during the ongoing treatments; therefore, women had to rely on their limited English or other South Asian staff to communicate with the health professionals. This woman described her experiences of being vulnerable but felt that the health professional's approach created a "safe" place in a strange environment while she was going for her first x-ray session:

> Respect is when any human being has come over to your home to visit; you should talk to them with politeness and kindness. You talk with love, and acknowledge them, regardless of who comes to your home. I always talk to everyone with respect because they are all human beings. I want others to speak to me in the same way as well. I am so afraid inside sometimes, especially when they did the x-ray the first time, but the nurses and therapists were very kind and

> stayed on both sides of me and told me that it was going to be all right. They told me not to be afraid and told me that they were together with me and that they were there for me. (A retired grandmother, Sikh)

This excerpt indicated the broader meaning of respecting the other when in a relationship. Women shared that health professionals' ability to acknowledge them as human beings when they were guests in the clinic allowed them to feel at home in a strange environment. For most participants in this study, this was a basic principle of being in relationships, an inherent aspect of humanity and social relationships. There was congruence between how South Asian immigrant women treated guests in their own homes and how they envisioned being treated by the health professionals in the clinic. Stories of being acknowledged indicated that South Asian immigrant women were the focus of health professionals' care and attention.

Women's stories indicated that health professionals tried to understand their perspective and appreciate their contributions to the health professional–client relationship by acknowledging their individual experiences as those of a South Asian immigrant woman. In the following excerpt, this woman, who had radiation to her skull, described her experiences of feeling at home in the clinical setting. She felt acknowledged and respected when the health professional treated her as she would treat a guest in her home by taking care of her:

> I had built a relationship with them. If they had been rude and did not have patience with me, then I would not like to go to a place like that, but they were so nice and they encouraged me. They respected me by welcoming me and putting my jacket on and my toque. Because I have to go underneath the machine and

> I have to take my toque off. They helped me on to the stretcher and on to the table and put the cushion underneath my knee and they put screws on the side of my head, you know for the machine. These were behaviours of respect for me. (Retired with grandchildren, Christian)

This same woman, in the following excerpt, was grateful that she was treated as a human being rather than a patient in the clinical setting, because their putting on her toque dignified her and made her feel whole again after the radiation treatment. This story indicated that respect did not need to be created by extravagant details; sometimes, the small things made a difference in the amount of respect, or lack of it, experienced within the health professional–client relationship. South Asian immigrant women's experiences and perceptions indicated that health professionals took an open approach that did not allow for assumptions of cultural taboos to interfere with acknowledging the other. In the following excerpt, the woman's description that she "felt like a human being and not an animal" indicates the ethical respect she felt we should bestow on humans in comparison to animals because of the hierarchical order of the world:

> Yes it was in my heart and in my soul that I felt the respect. I felt that I am a human being and that I am not an animal. They treat you like a human being. They talked to me like a human being and treated me like a human being. They talked to me with respect, with ijjat [Hindi word for respect]. Even now when I go to the clinic they still talk to me in the same way; with respect. It feels like I am respected as a human being when people talk to you nicely and respect you and you want to do the same for them too. (A retired grandmother, Hindu)

Being acknowledged and accepted as a human being was seen as a key characteristic of respect throughout women's stories of their health professional–client relationships in the clinical setting. It seemed important for women to be valued for their human worth and to be recognized for their contribution to humanity regardless of their cancer condition. Women felt that health professionals made genuine attempts to understand their ethnicity, which demonstrated respect. In addition, South Asian immigrant women felt that their existence was recognized when health professionals showed respect through acknowledging them as an equal part of the health professional–client relationship.

*Being Greeted*

Being acknowledged and accepted in the relationship through a greeting was especially important for most women, especially those making daily visits for radiation. South Asian immigrant women suggested that being greeted was the social aspect of being in a health professional–client relationship. Women told stories of how they personally acknowledged the other person as part of this world simply by greeting them at the beginning of the relationship, because this acknowledged the person's existence. They felt that verbal exchanges with health professionals at the cancer agency setting reduced their fear of treatments and allowed them to feel at home in a clinical setting. Women described that health professionals' genuineness when greeting women went beyond mere courtesy; it acknowledged them as the other human being in the health professional–client relationship. Most women described courtesy as being polite but that greeting was a social expectation of being in a health professional–client relationship.

South Asian immigrant women's expectations of respect were a component of their personal experiences, which they brought to the health professional–client relationship. This perspective was connected to their life experiences, through which they expressed themselves in the health professional–client relationship. Health professionals also brought their way of being, their standpoint, to the relationship, which took place in the context of the outpatient follow-up clinical setting.

The clinic was an institutional setting with multiple sets of policies and guidelines through which health professionals' orchestrated their daily work life and where South Asian immigrant women brought the realities of their life experiences. South Asian immigrant women's stories of respect are interwoven with their perceptions of health professionals trying to humanize this institutionalized clinical setting by acknowledging them as people with life experiences, people who mattered in the larger realm of the health professional–client relationship. The women felt that because health care experiences were generally very invasive and affected the whole person who was suffering because of the cancer condition, as voiced by this woman, greeting them before provision of care humanized the relationship:

> Yes, it first depends on the behaviour and the way that a person talks to you, and then it is how the person cares for you or provides care for you. Provision of care comes afterwards, because first you have to respect that person by saying "hello" to them or behaving in a respectful polite manner, then you're going to provide the care. If a person is rude to you in the beginning then you're going to expect that rude kind of behaviour and rude care. Because if you are not polite in your

behaviour how can you provide polite care? (A mother with young children, Muslim)

Most women described that greeting the other in a health professional–client relationship was of the utmost importance because it acknowledged the other's existence before health professionals began the cancer treatment procedures. The physical setting, which included a common lounge where women waited before going in for the consultation, facilitated the opportunity for health professionals to greet women before they were taken into the examination room. For example, it was possible for health professionals to provide personal care while the oncology or licensed practical nurse rather than the nursing unit clerk walked women into the examination room before doing an assessment.

For most women, being greeted and respected allowed them to feel confident and comfortable within the health professional–client relationship. This characteristic of respect welcomed them into the relationship, which, in turn, allowed them to feel like partners within the health professional–client relationship.

South Asian immigrant women described that part of greeting an individual was providing nourishment and a place to sit when welcoming guests into their own homes. This experience was congruent with women's descriptions of their being greeted and welcomed by health professionals who were their hosts at the clinical setting:

> Yeah they always greet you and welcome you and say, "how are you" and "are you comfortable?" I remember feeling so confident when there was all this attention. They would ask me if I wanted juice, water, or cookies while I was going through the chemotherapy treatments. Sometimes I was there for five hours.

> They always ask me for juice and gave me a warm blanket without asking. When I go the clinic it is the same there as well. They always say hello and bye-bye. Even after the treatment and everything, they will come and help me dressing up you know and always say goodbye, see you tomorrow. That makes me feel good in a respectful way, yeah. (A mother, Hindu)

For most women, being greeted and respected included not only the initial greeting when entering the relationship but also their exit, when health professionals bade them good-bye. Women felt respected and released from the relationship when health professionals took the time to say good-bye after the cancer-related treatments were finished for the day.

Although most women felt that health professionals genuinely expressed respect when providing care within the confines and constraints of a clinical setting that set limitations on building health professional–client relationships, some women felt brushed off when health professionals did not greet them or say good-bye at the end of the relationship, as described by this woman:

> Doctors are different in their approach, you know. I had two doctors, one always said hello, but the other one, he used to walk into the room and straight away, he would say, "what the problem is and what not." He never took time to say hello or good-bye, he just asked me right away. You know people are different backgrounds and what not, but it made me feel like I could not talk to him openly. You don't feel good at this time. (A widow with grandchildren, Muslim)

South Asian immigrant women's perception that showing respect for fellow human beings by acknowledging the "other" through greeting was an inherent underlying

assumption of respect and was apparent throughout the findings. For most women, being greeted was the first step toward respecting the other. South Asian immigrant women shared that we acknowledge a person by greeting them; however, we do not always have to verbalize respect, because we can accept the other by smiling at him or her.

*Nonverbal Ways of Bestowing Respect*

According to most South Asian immigrant women, a greeting could involve verbal and nonverbal behaviours, such as a nod, a smile, or eye contact. Women felt that greeting a person through the use of verbal or nonverbal actions gave them importance and allayed fears. In addition, some women felt that respect gave them a place within the health professional–client relationship, even through nonverbal eye contact, as this woman voiced:

> Respect is something that you know it, you notice it. You notice it because when people greet you, you look at the face, you know and you look in the eyes, you can make out whether you are liked or not, I don't know about you, but I can, I can look at somebody's eyes and the way they greet you, and smile at you, you can make out if they respect you or not. (Retired mother, Muslim)

Some women implied that most health professionals' facial expressions could indicate respect at the beginning of the relationship. These women felt that a health professional's facial expression could tell a story, allowing women to perceive respect or not, as illustrated by this woman:

> Well in one's life experience you meet some people that you don't at the first impression and they are impolite and you don't like them. Then after a while it is just the way that he or she talks and you realize it's just the way that he or she

> talks [and] maybe it is his face or the facial expression, tone of voice but he is really nice. And she does whatever she can maybe some people just don't look very nice on their facial expression, but they're a good person, but it is just the way that they show their face, their facial features. (A mother with married children, Sikh)

*Being Treated Equally*

Most women felt their ethnicity was valued when they were acknowledged and treated as equals in the health professional–client relationship in the clinical setting. Findings indicated that health professionals' capacity to treat people as equals invoked inherent feelings of worthiness for South Asian immigrant women. Women witnessed others being treated as equals or partners at the clinic, regardless of their nationality, gender, or age. This woman illustrated her experiences of "sitting there all day" and witnessing other people from all walks of life receive the same respectful care as she did:

> From my experience what I see is that they do the same care, they provide the same care for everyone regardless of who they are and where they're from. You see this woman who was there from another country. She came over here and she got lung cancer and they treated her same as me. Her husband had lung cancer and then she got lung cancer as well. They treat everybody the same, whether they are Chinese or White or Indian, it did not matter. I see that all day when I'm sitting there getting my treatment. They treat everybody the same. They provide the same care to me as they do for the other women or men. (A grandmother, Hindu)

This demonstrated that they were accepted as a human being first and as a "South Asian immigrant woman" with a cancer condition, second, thereby creating a human-to-human relationship, making the women feel more comfortable, safe, and respected in spite of their cancer condition.

Some women felt that by acknowledging them as people, health professionals tried to understand their situations in life, their individual perspective. Being respected and treated equally regardless of age, gender, ethnicity or class empowered the women as they dealt with cancer conditions such as breast cancer, which invoked feeling of fear. Gender was noted as being an important part of being a South Asian woman. By treating women as equals and respecting their humanity, health professionals allowed the women to be themselves and to contribute holistically to the health professional–client relationship. This participant felt that one should not expect more than a person can contribute to the relationship:

> Respect means being friendly and accepting you for whatever person you are and being helpful and giving you space to be who you are. We are all human beings, so therefore we have to be civil to each other and talk to each other with politeness and treat each other well. That is whoever it is; you should treat them as a human being and talk politely. Yes it is acknowledging other people, respecting of where they come from or family that they have or what culture they have. People should not expect more than what we are and should treat everyone in the same way, that is what I would say is respect. (A widow with children and grandchildren overseas, Christian)

Although some South Asian immigrant women had challenges expressing themselves because they were non-English speaking and in a clinical setting with mostly English-speaking health professionals, they expected to be acknowledged and respected as human beings rather than as South Asian non-English immigrant women. This woman illustrated her experience:

> I am saying that they treat everyone the same, as a human being regardless of who they are. To me respect means acknowledgment, caring, and accepting of another human being. You know when I came into the clinic, I never felt that I was different from anyone else, I always felt comfortable and safe. You know you always have fear when you come back every time you come back for an appointment, you feel fearful, but you know that they are doing all that they can. So to me respect means being polite, regarding others as persons, as individuals, and knowing that they want the same thing that we want, which is to be acknowledged. I think if you accept others regardless of what or who they are, that is respect for me. (A retired mother, Muslim)

South Asian immigrant women felt safe and comfortable when they were respected as equals in the health professional–client relationship. They felt that they were treated as equals rather than mere patients who were being treated for cancer in an outpatient follow-up clinical setting. Although women described these as characteristics of respectful relationships, they needed explanations about cancer and its related treatments to make decisions about their health.

*Ways of Talking When Providing Information*

The way of talking while providing detailed explanations about cancer during women's clinical visits was seen as another way of bestowing respect. Women felt that this characteristic played a key role when health professionals provided information regarding the type and stages of cancer and its related chemotherapy or radiation treatments, its symptoms, and treatment side effects in an engaged manner. Most South Asian immigrant women felt that health professionals' approach and their "way of talking" or engaging with them while providing information facilitated their understanding of the cancer condition and its process. This information helped South Asian immigrant women make decisions about their choices of treatments to take in order to cope and function in as normal a way as possible under the circumstances. In addition, most women felt respected by health professionals who took the time to engage with them when talking to them about information, which was necessary to make decisions that would affect their families. This form of engagement with women allowed them to be a part of the conversation and retain valuable information about their bodies. This younger woman of 40, who had a child, felt respected when health professionals made a conscious effort to include her when providing explanations about her cancer condition:

> The doctors' and nurses' responsibility is to take care of the client by telling them all they know about the cancer, because it is important for us to know. I remember when I first found out about my cancer, I wanted to know all that I could. When I came to the clinic, they told me all the information that I wanted. The way they talked to me, with politeness and knowledge together was very respectful of us who have cancer. I felt like I could ask those questions if I wanted to, I felt like I

> was included. They explained everything, told me what I would expect from the procedures and the side effects, and let me make some decisions about the chemotherapy or the radiation, because these affected my job and family life. This is their job and they know all there is to know and when they tell us, it is respect. (A retired mother, Muslim)

Generally, women felt that health professionals' ability to engage with them in a respectful manner increased their understanding of what their cancer journey would be like in light of their everyday life experiences. The women indicated that the health professionals' approach and communication style while providing explanations allowed them to understand the possible complications and side effects of cancer and its related treatments. This valuable information helped them when they had to make decisions about their health care that would affect their work and family life.

Understandably, most women were overwhelmed by the cancer diagnosis, the related treatments, and the unknown future. Most felt that cancer patients have to deal with a host of things, such as their mortality, the possibility of leaving their loved ones behind, and having to make decisions about their employment and quality of life in relation to the cancer-related treatments and its side effects. Some women felt that the health professionals' approach and engaged manner during their clinical visits decreased their anxiety and apprehension about their cancer conditions, especially when they were fearful of the future. This, in turn, was perceived as respect by most women. This woman had been diagnosed within the past 5 months, had undergone surgery, and was going for daily radiation treatments at the time of the interview:

> The only thing is that when you first go in for all the treatments and you find out about cancer, your brain is all occupied, thinking of all the stuff, you know. I always felt respected in the way that they talked to me and that was the main thing for me because they are so friendly here and they talk friendly with a lot of smiles. They will escort you and they will go with you and they show you which room that you have to go into. In the radiation room as well they have to stay with me and they always work together. When I left the clinic after the treatment I felt so safe. I was not scared especially the first two treatments, I felt free.
>
> (A retired grandmother, Christian)

As the previous excerpt states, some women felt "free" leaving the clinic after receiving treatments. These women felt that health professionals' ability to provide them with proper explanations in a nurturing environment during clinical visits helped them to make sound health care decisions, leaving them feeling safe and comfortable, regardless of the ambiguity of the cancer condition.

Most women were provided with interpreters during their clinical visits if they or their family members did not speak English. Health professionals or nursing unit clerks generally phoned the women before their initial visits to book appointments. At this time, the women were asked whether an interpreter was needed. However, some health professionals' were not aware that most women from the Fiji Islands may not fully comprehend Punjabi, because they spoke Hindi as illustrated by this woman:

> But you know the interpreter was an Indian woman who was Punjabi, but she spoke Hindi to me. Some of the Punjabi women speak Hindi very well, whereas others do not. You know in [name of country] you cannot even tell whether they

> are Punjabi or not, because they speak Hindi, but over here the Punjabi women speak very deep in their own language, so it is hard to understand them. You know in the chemotherapy clinic there are some Punjabi nurses, but one of them does not understand Hindi, you know. (A grandmother, Hindu)

Most women felt "at home" in the clinical environment regardless of their ability to speak English because of the way health professionals "talked to them." They felt that health professionals respected them as individuals and approached them with friendship, which allayed their fears of being in the clinical setting. This allowed the physical surrounding of the clinic to "feel like home," especially when they had to make daily visits. This woman described that health professionals' way of talking and engaging with her allowed her to "feel happy" and respected, which was important at this vulnerable period in her life, when she had a host of other things to deal with:

> It is the way that they talk eh, you're not alone. Somebody's around you and you're not scared or anything, yeah. The way they talk to me very friendly and with respect. They explain everything if you don't understand it. It felt very good in my heart and it made me happy. When someone talks rudely to you then you feel bad, but if someone is polite and respectful then you feel happy. And when people talk to you with care and love then you feel happy. I feel happy when they talk to me with respect. (A mother with married children, Sikh)

South Asian immigrant women described that most health professionals respected them when they took the time to engage with them with politeness and respect, regardless of their busy schedules and time constraints during the day. Even at these busy times,

most women experienced respect and saw health professionals as human beings, as described by this woman:

> You know sometimes health professionals at the clinic maybe are busy and are not able to be polite it may be because they're busy. But it may be once in awhile that they are not polite. You have to excuse them because they are busy but every other time they are very polite and very respectful to you. However I'm not saying that it happened to me because I was there for twenty-five days it never happened to me. They were not disrespectful at any time but I'm saying that if it ever happened we should be able to excuse them. (A widow with grandchildren who reside overseas, Christian)

Most South Asian immigrant women's stories of their relational experiences and the realities of life that they brought to the health professional–client relationship were simple characteristics of respect that they enjoyed in their daily lives, such as politeness and gentleness in the tone of voice. Women realised that health professionals might not always be able to display these characteristics of respect because of the number of things that they have to remember when working with a number of patients in a busy clinical setting. Politeness and gentleness in the health professional's tone of voice and way of talking were seen as respectful by this non–English-speaking woman, a grandmother who had immigrated to Canada 30 years earlier:

> It is the way one speaks to another person, and when you talk to another person, you are polite and kind. You take care of the person by being polite and respectful and talk in a gentle voice. The way you approach others by being polite,

> courteous, and gentle in your way of talking to others is respect. (A retired grandmother, Hindu)

Most women recognised that an outpatient follow-up clinic in a busy cancer agency does not always allow time and space for the social etiquettes of building positive and respectful health professional–client relationships. This is especially true when technical clinical demands were placed on health professionals who had to orchestrate between 8 and 10 patients while providing efficient and precise care for women in the chemotherapy clinics. Participants recognized that social exchanges within health professional–client relationships did not occur only verbally but that subtle tones of voice also carried messages of respect or the absence of it in health professional–client relationships.

*Tone of Voice*

Most women felt that a health professional's tone of voice conveyed respect or not when they talked to clients. Tone of voice included the harshness, gentleness, or level of the voice. During the initial part of the relationship, respect was conveyed by the tone or depth of an individual's voice, thereby setting the tone for the relationship at the beginning. This woman described how the health professional's tone of voice and manner portrayed respect:

> I know that they respect me even if I do not speak English. One can feel the respect by the tone of voice and the way they talk. If you talk with anger or with a loud voice [pretending to have anger] and the other is a very polite manner and they say bye-bye. You can tell the difference, respect is felt through in this way of talking. Nobody has ever said anything to me in a disrespectful manner. You can

> tell the difference by the tone of voice and how they talk with you. (A mother with married children, Sikh)

The overcrowded clinical setting, busy schedules, and time constraints set the stage for a lack of respect when over-stressed health professionals had to follow stringent procedures and protocols for cancer-related treatments. This indicated that such a clinical setting was not conducive to the respectful tones of voice that would indicate respect for South Asian immigrant women, as illustrated by this woman's story:

> Sometimes the nurses are very busy and they may sound rude and abrupt. At this time they may not pay attention right away, but you have to forgive them. The tone in their voice tells you that they are busy, but they have not ever been this way with me, but I am saying that I have seen them, when they are always running because they have so many people to look after at the same time, you know in the chemotherapy room. (A widow with some of her children and grandchildren in her own country, Hindu)

A tone in the health professional's voice was perceived as either respectful or not. Some women described that it was not only the words in the exchange between the health professional and the woman but also the tone of voice used by her or him that indicated respect. For this woman, respect was delivered through the health professional's tone of voice, along with the action of voicing "hello":

> Respect is not only just being "oh yeah, hi, how are you" I think it is everywhere and it is not only in the way that I address you, because if they were rough with me when they talked to me, I would feel it, even if I do not speak English. It is

> also the voice and how loud it is or how gentle it is. (A mother with married children, Sikh)

Women did not consider raising their voices to be heard as being respectful. This action did not acknowledge people as individuals but instead dismissed them. Most South Asian immigrant women described that respect was conveyed not only verbally but also through the tone or level of voice used when talking to others. This woman shared her life experiences:

> Speaking politely to the other person and acknowledging that person by saying hello and greeting them is respect. The language that is used and the way you talk to the people, you know sometimes we raise our voices and talk loudly because we want to be heard, I do not think that is respectful. We can say the same things in a different manner, whether it is gentle or it is high pitched. The way you talk to people and the tone you use is important because it makes them feel acknowledged and respected. (A mother with married children, Sikh)

The way of talking as a characteristic of respect was described by most women as an important aspect of respect, especially when communicating difficult information. Women described that health professionals had to be conscious of paying attention to details such as their tone of voice and communication styles when providing information and care for clients. According to the women, this could be achieved by attending to the person and being present when talking to clients about complex cancer-related treatments and side effects. Health professionals' ways of talking and attending to their needs were perceived as respect by most South Asian immigrant women.

*Attending to the Person*

Women felt inherently worthy of respect and attention when health professionals showed genuine concern and worry by consistently asking them about their health and well-being while the women were going through treatments. Most women described that health professionals' capacity to provide consistent care and attention created respectful relations. To illustrate this notion, women alluded to feelings of being special and important to the health professional who was providing care. Attending to the person, who was a woman journeying through cancer, was a key characteristic of respect for most women. According to women, this characteristic was a small part of the larger meaning of respect within human-to-human relationships.

Most women described that health professionals' ways of being, their openness while interacting with them, and the attention given to women were all part of respect. This woman described that the way of being was an individual's make-up; however "attending to the person" was the action behind the health professional's approach:

> No I just was thinking about the meaning of respect and I came up with attention. Especially in this situation you know with my illness. I need something you know in action and action to me is paying attention, I was thinking that. Yes I have been thinking about attention. I'm thinking it is not only the way of being, not only the openness, but attention as well. I feel that they are doing their job when they are up to date with their information so this is their attention to me and it is respectful. It is attention that they pay me. Attention is together with their way of being, when I think of the meaning of respect. (A mother with young children, Muslim)

South Asian immigrant women experienced that health professionals were genuinely concerned and worried about how women were coping with cancer and its related treatments when they consistently inquired at each visit. Some women described their feelings of connecting with health professionals when chemotherapy nurses took the time to listen and to be present while providing chemotherapy treatments by making sure that they were pain free while needles were being inserted:

> The example that I can give you is that they attend to me. It is that they are worried and concerned about me, they care about me and they attend to me. I know that they are doctors and nurses but they are very friendly to us. I am a patient over there, and they look after me by paying me regard and are attending to me. They are careful when they put the needle in and start the medicine. (A grandmother, Hindu)

These experiences were described very vividly, as if women were reliving them during the interview sessions. Most women felt a connection with the health professional who was also a human being while providing care to another human being who was suffering from cancer.

These feelings of connectedness took on a deeper meaning when women described their experiences with health professionals who were present for them by praying for them. Most women described health professionals' capacity to be attentive and caring as being respectful and nurturing but were pleasantly surprised when some nurses infused prayers during their chemotherapy treatments. Women found this healing and felt special, as described by this woman:

> There is one nurse, she is very good. She does a prayer before she gives me the injection or needle. She tells me that she is praying to the lord Jesus before she gives me the injection. She always does that. Just before the needle goes in the hand, she does the prayer. You know that when we go to the hospital we're afraid of everything there, we don't know what we're going to get there, how the blood will go inside us when they are giving the blood to us, and how the injection will go in, but she makes it very safe for me, very comfortable, a good experience and she relaxes us first. She does it very nicely. (A widow with children in her home country, Hindu)

Although I assumed that this experience might be disrespectful for the women because of the religious connotations and differences in religious beliefs, women described these experiences as being more healing and respectful than not. Some women described experiences of feeling peace, safety, and happiness when this type of attention was given to them, as voiced by this participant:

> They made me feel like a human. They made me feel special because regardless of me having cancer someone was looking after me. It felt good to know that I was cared for in the kind and polite manner when they paid attention to me. They treated me like a human being and they actually cared for me as a human being not like a patient. You know it made me feel very happy and like being at home. I always looked forward to going there for the treatment. I felt very happy in my heart, I felt very good and very peaceful. I wasn't scared. (A widow with children and grandchildren overseas, Christian)

For most of the women, clinical visits had a special meaning because they experienced human connectedness when health professionals took the time to provide attention and care at a time in their life when they needed it most. These positive actions connoted respect for the women. South Asian immigrant women shared that when they were diagnosed with cancer, they had to make lifestyle changes, which included changes in their diet, the way they dressed, and their social life. This woman shared her experiences of respect when health professionals paid attention and cared for during her radiation treatment:

> It is the way that they act and do things for me and listen to me. You know that sometimes it does feel that they pay so much attention and care for all our needs. Well it is all in the way that they attend to you when they don't attend to you well then you don't feel good really; it is just by the behaviour that you feel good. If they don't attend to you then you don't feel good, you feel bad. They always looked after me well and they changed the bag [colostomy] for me. The radiation therapist didn't change the bag; they just checked the bag. The nurses changed the bag for me if it needed changing. If it needed cleaning than they would take a cloth and clean it for me. (A retired mother with married children, Sikh)

Health professionals' capacity to attend to the person by being present was valued, because it bestowed respect on the women. Participants described feelings of happiness because they felt health professionals made them feel special and important when visiting the clinical setting. This woman illustrates her experience:

> Usually you don't get that kind of attention you know and when I got all this attention here I thought you know this is excellent. I don't know how much they care for other people and what not, but I felt very happy inside and I say to myself that you know, "these people are so wonderful" and they know what they are doing here, it is a really wonderful thing because this is what we need, especially with cancer, you need kind and attentive people like that who show some respect for you and do things for you, that was the main thing. (A mother with grown children, Hindu)

Women described experiences of respect when health professionals took the time to listen to them and provide attentive health care. South Asian immigrant women felt that because cancer was seen as a condition under which most people are faced with their mortality, health professionals' capacity to attend to the person was important, especially while that person was going through complex and lengthy cancer-related treatments in the clinical setting, which made women feel very vulnerable.

### South Asian Immigrant Women's Experiences of Respect within Health Professional–Client Relationships in the Clinical Setting

Most South Asian immigrant women described that the meaning of respect was influenced by their beliefs and values, which were, in turn, influenced by their heritage and upbringing within the South Asian community. According to South Asian immigrant women, these beliefs and values regarding respect might be ingrained within societal culture; however they are practiced individually and daily according to each person's personal morals and values. Some women indicated that although culture and heritage might play a large role in their experiences of respect within health professional–client

relationships, they saw respect as an inherent human desire to be acknowledged and accepted. This section of the findings describes how South Asian immigrant women's reflections on their heritage and personal frame of reference relate to relationships. As well, it describes how their everyday life experiences provided a lens into their experiences of respect within health professional–client relationships in the outpatient follow-up clinical setting.

### *The Influence of Women's Heritage on their Experience of Respect*

Women described that societal and individual practices and meanings of respect were interwoven and reproduced in routine, everyday interpersonal relations, making for a more holistic meaning of respect within health professional–client relationships. As the analysis unfolded, it became apparent that some characteristics of respect were more similar than not across the South Asian immigrant population, regardless of their country of origin, as described by this participant:

> Well it is the way that a person is brought up, you know culture plays a large part in who a person is and what respect will mean to them. For me as a South Asian woman it means that I am a woman who has these values that make me a South Asian woman, however I may do some things that are a little different from other South Asian immigrant women because of my personal experiences, how I was brought up, and how I understood respect myself. (A retired widow with grandchildren, Muslim)

Women understood that language and words used to describe respect and its attributes might be different because of culture and ethnicity; however, the behaviours or

ways of bestowing respect were viewed as similar among women of all ethnicities, as voiced by this woman:

> It would be the same thing, just the same thing. There wouldn't be a difference between the Canadian woman and the immigrant woman. Yes, I think it would be the same for South Asian women as others, because you would talk with respect in the same manner, with politeness and kindness, you would treat others in the same way as any other woman from another culture. It does not matter what race a person is, respect should have the similar meaning. Only thing is the language. It is our way of speaking that is different, for example: we might say "ijjat" (respect in Punjabi) and Canadian women say "respect." I think this is different, but other than that I don't see respect being different for me than any other woman. (A grandmother, Sikh)

Most women described the importance of elders as well as children both deserving of respect in a family unit, regardless of age. However, women stated the elders in the family deserved respect in a different way because of their age and life experiences. Women described different forms of relationships that demanded different forms or ways of creating respect. These different forms of relationships were understood as being influenced by culture, especially by women who lived with their extended families as grandmothers and helped raise their grandchildren. This grandmother described her role in the family unit and her meaning of respect as being influenced by her relations with her family and her beliefs:

> You have respect for different types of relationships. For example, you have respect for children and grandchildren, and other family. All of these individuals

> will have respect for us. We have respect for our children and our grandchildren. God has respect for us and we have respect for God. God has given us the children so we are taking care of them in our home, which is respect for us as women. Providing care for the grandchildren is regarded as respect in other words. God has respected me by providing children and grandchildren for me (participant is praying with her hands together at this time). (A grandmother, Sikh)

Most of the older South Asian immigrant women's relational experiences were deeply embedded within their cultural perspective, which was viewed through their lens of being part of the extended family that provided support. Women who helped raise grandchildren felt this to be a very important part of their contribution to their families and to society. These women's frame of reference for relationships was viewed from these life experiences and perceptions. For them, respect within personal relationships with extended family members was very important at all times, as stated by this woman, who relied on her family's support:

> I would say that it is different with family, when family comes and goes to my home and they come in to see me, I blend in with them with respect because they respect me and I respect them, we become one with them. I become one with my family members because they respect and attend to me and I respect and attend to them, we become one instead of different people. When my family comes and they bring love and caring for me it is a form of respect as well and because they bring love and caring for me, I give them love and respect back. I feel happy and joy and they feel happy and joy in their heart. That is a form of respect, this love

> and caring and joy is a form of respect, and because of this mutuality, we blend into one another, because of this blending, my illness is forgotten for this time being. My illness becomes lighter and I find peace during this time that I am with my family. (A widow with grandchildren, Hindu)

Respect was also defined as being a good host by providing the hospitality of your home, a comfortable place to rest, and nourishment, and by simply sharing of the "self" with the other, whether family, friends, or guests. Welcoming guests and family at the door, seating them, and providing them with nourishment was seen as part of the South Asian heritage and culture. I witnessed these behaviours when conducting the interviews, because I was not allowed to leave without having a cup of tea and sweets.

> Well the meaning of respect is for example, when you just came in I greeted you at the door and I asked you what you will eat, dinner or drink tea or juice. In addition, I give you a seat. On the other hand, if I do not acknowledge you and ask you to have something to eat or drink or did not even ask you to have a seat you would feel disrespected. Respect is making sure you greet the person, give them regard, and acknowledge them. (A retired grandmother, Christian)

For some of the older South Asian immigrant women, talking to men who were not family members was difficult because of cultural influences regarding their gender roles. These women shared that they felt uncomfortable generally talking with men, because they were not used to this behaviour, especially if they could not speak English. Therefore, being cared for by female nurses or radiation therapists created comfort and ease for most South Asian immigrant women. This woman always took her son or her husband to the appointments that involved interactions with male health care providers:

> Well I don't talk to the doctors, I just say bye-bye when they say bye-bye; I never talk with them, neither they nor I. I never talk with the doctors directly, the males, I share with the nurses only. When the doctors say bye then I say bye, otherwise, I do not say anything. With the nurses, I have interactions, not with the male doctors, because I am not comfortable talking with them. (A retired grandmother, Sikh)

Although South Asian immigrant women experienced respect within health professional–client relationships at this outpatient follow-up clinical setting, most felt uncomfortable with male health professionals because they had been accustomed to female family physicians. In addition, some South Asian immigrant women felt embarrassed when being exposed to and touched my male health professionals because they were not used to this.

### *Touch*

Some of the women had not been hospitalized before and had no previous contact with some Western cultures because of their advanced age and because they had not worked outside of their homes. Most women in this study had South Asian male or female family physicians for regular health-related issues. Some, especially breast patients, experienced shyness during their clinical visits when male health professionals had to touch them while providing radiation treatments. However the women felt that health professionals helped them through this experience by providing clear explanations during these uncomfortable sessions, as this woman experienced:

> Respect also means, you don't like anyone touches you, your breasts, but it is a treatment, you can't help it right, you have to go through it. I always come home

> and tell my boys this happened and they said, don't worry mom, just go through the whole treatment and they are just giving you the treatment and you will be OK. Well there are some things that we don't, I don't want anyone touches me, because it is not like that in our community, what ever you say, because we are not used to it, but it is the treatment and you can't help it. (A widowed grandmother, Muslim)

Women described that health professionals went out of their way to portray respect when they had to touch women, regardless of the small window of time they spent with them during the radiation treatment. Women felt that health professionals preserved the humanity within the health professional–client relationship by respecting their femininity and vulnerability even though this was a clinical setting in a cancer agency. Women shared that health professionals showed respect in their approach as they uncovered women's body while providing treatments. This woman perceived health professionals' actions during the treatments as being respectful:

> For example they put me under the machine gently and they touched my arm and picked up my arm and then they covered me with the gown. All of the doctors and the nurses and the therapist's were very good when they touched me and they were very gentle with their hands with the way that they treated me with their hands and their behaviours because if they had not moved me gently with their hands I would know. I would feel the roughness when they touched me if they were not gentle. (A retired grandmother, Hindu)

Women shared that they had to get used to their body's being touched and exposed to male health professionals during cancer-related treatments. South Asian

immigrant women described that health professionals who took the time to avoid touching or exposing the body unnecessarily respected their sense of humanity and femininity. Women felt that the health professionals' approach ensured privacy, which was deemed as respect.

*Privacy*

Women experienced respect in the clinical setting when health professionals took the time to cover the exposed body during their radiation treatments. They described that health professional's minimized exposure of their female reproductive areas of their body by placing a drape over them. Some women perceived that the need for privacy in relation to the female body was primarily influenced by their South Asian culture, regardless of their age. Participants also shared that privacy is probably inherent in being a woman; however the extent of this need for privacy might be unique for each woman depending on her past experiences:

> What I'm saying is my need for privacy may be different from other women's need for privacy, because I want the door closed, I would like the blinds closed on the windows, and I can't change where the windows are open at all. That is a way of respect as well, it is giving someone privacy. What I am saying is that they give you the gown and close the door and I would change. For me that is respect and regard for me as a woman. I think that it would be the same for any woman, though I think it is the same for any women of any ethnicity, not only for South Asian. (A mother with married children, Sikh)

Most participants, regardless of their age, experienced shyness and discomfort when being examined by male health professionals because of modesty and discomfort with exposing their body, especially the breast area, as described by this woman:

> As a South Asian woman, I have shyness and want privacy, but they were very good with me and cared for me very well. The first time I felt when they touch my breasts it was strange and slowly I got used to it (Laugh). It was funny and strange because they touched me and then marked it with a pen they put marks on it, so you feel it, kind of funny. The first time you feel shy and want privacy, because two or three guys are there, most of them are guys and you're not used to this. (A retired grandmother, Christian)

Some women felt that shyness was embedded in their culture because they had not been exposed to the Western style of dress. Most older South Asian immigrant women had retained their traditional mode of dress even after immigrating to Canada almost 30 years ago. However, they also felt that shyness was something that might be common among the older South Asian immigrant women, as shared by this woman:

> I don't know but I think they're bit more open, the Canadian women. We, the South Asian women, are a bit more shy because we have never come in front of guys, so it is a little bit different for South Asian women. But maybe this is more for older South Asian women than younger ones, I don't know, I can only speak for myself. (A retired mother, Hindu)

The length and type of procedures when preparing a specific area of the body for radiation treatment normally increased the exposure time of the body, as accuracy is required for an effective radiation treatment. This increased exposure time of the body

was compounded when two or more male or female radiation therapists had to work together to align the radiation treatments. Despite these circumstances, women described their experiences of feeling respected as South Asian immigrant women and felt valued by health professionals who did not expose their bodies during the treatments, as shared by this woman:

> For radiation, over there we have to remove all the clothes and you put the gown on and as soon as you take off the gown while they are giving you the radiation they cover you, but they always cover you. For example they open the first breast and they keep the rest covered and then they open the other. They made sure I was covered and then they uncovered the other part of my body but made sure that I was still covered and that I still have my privacy. (A retired mother, Hindu)

Most women described that both male and female health professionals created their experiences of privacy and respect. Privacy was important for most South Asian immigrant women in the clinical setting, because it related to respect for the South Asian immigrant woman and her body. However, women recognized that the need for privacy and respect might be similar for all women, regardless of ethnicity. South Asian immigrant women described that health professionals' approach and their way of being indicated compassion when they respected them by attending to their needs for privacy.

### *Compassion*

Most women described that health professionals were kind and considerate while delivering chemotherapy and radiation treatments. The health professional's approach was perceived as compassionate when they paid attention to South Asian immigrant women's needs, such as by offering juice, water, and warm blankets during their

chemotherapy treatment sessions. One woman felt respected when cancer information provided was not only helpful but was given freely, so she did not have to battle for anything. These stories of health professionals' genuine concern and attention for women's well-being and caring for women with respect corroborates that health professionals tried to practice person-centred care. This was perceived as compassion for someone who was already dealing with a lot of things:

> I feel that maybe being more compassion maybe it is better to be more compassion, especially in health field. When you feel compassion then you give people a chance to be in themselves in the relationship. You know that something has happened and they will need to know sooner or later, so it is better to be in the office and talk to them in a nice manner. I think its more compassion to talk kindly to this person. It is more human it is not that it is more respectful or less respectful. In my opinion I didn't feel offended but I feel it would have been better and more compassion to be told, what kind of cancer I have. I have this disease I have to do something you know what is, then tell me, but it is compassion that is respectful. (A widow with children and grandchildren in her home country, Hindu)

Health professionals' capacity to listen to women's stories and their ability to be attentive to their suffering during their clinical visits were experienced as respect by most women, especially when the woman already felt overwhelmed by the cancer condition. Most participants suggested that health professionals might be gentle and caring because they provided cancer care services at the cancer agency, as described by this participant, who felt special:

> You know cancer is a death penalty and this is why they are so careful and gentle with you because of the disease. You see all kinds of people coming into the cancer agency and getting treatment, especially when I was in the chemotherapy clinic. The nurses do not care who you are; they treat you special regardless of who you are. They ask me about my pain and suffering that I have gone through and it makes me feel special. They ask me whether I am feeling good or not, how it has been since the last chemotherapy session and if I have any pain anywhere or not. (A retired mother, Muslim)

Some women perceived compassion and respect in the health professionals' approach and way of engaging with them regardless of the women's ability to communicate in English. These women felt that respect was conveyed by health professionals' actions and behaviours rather than by their words. This non–English-speaking woman, who had immigrated to Canada 30 years ago, described her experiences:

> That is what I felt, I felt the kindness, the sympathy, and the caring way they provided care for me and talked with me even if I did not understand or speak English I still understood the way that they provided the care for me. You know that person inside you, the person that is inside me, my soul; it understands how a person treats me. It is the human-to-human relationship that is the person inside us that gets touched when we get treated with kindness and compassion. They have been very good with me, and I can say that I felt respected when they were providing the kindness. (A grandmother, Sikh)

Most women described feeling special when they were treated with respect and compassion. They felt that health professional's ability to pay them attention and genuinely listen to their stories on a daily basis, without fail, promoted respect for their human suffering and personhood. These feelings invoked reciprocal respect for health professionals, which women described as inherent qualities of human beings.

*Reciprocity*

Most women described feeling respect for health professionals who took time to attend to their needs, especially during chemotherapy and radiation treatments. South Asian immigrant women described respect as a reciprocal process, one that invoked feelings for the "other" fellow human being. Women felt compelled to respect health professionals when their stories of suffering and pain were heard by health professionals, regardless of the number of visits to the clinic. Some women suggested that God would look after these health professionals who respected them as human beings by creating nurturing relationships. This woman felt that health professionals will be blessed because they provided care with respect and compassion:

> I feel very special at this time when they do these things for me. I feel compassion and respect for them too. I feel sadness that they are taking care of us even though we are patients. We are the ones with the diseases and illnesses, but they just take care of us, very patiently. I always think to myself that these nurses will get so many blessings from God, because they are taking care of us by running and getting anything that we want for us. (A widow with children in her own country, Hindu)

Health professionals' capacity to treat women as human beings invoked inherent feelings of worthiness and value regardless of differences. In addition, because women felt acknowledged in their health professional–client relationships, they felt reciprocal feelings of respect for their health professionals, as voiced by this participant, who was receiving chemotherapy:

> It feels like I am respected as a human being when people talk to you nicely and respect you and you want to do the same for them too. I feel respect that they are taking care of us even though we are patients. They give us the regard, attention, compassion, and care as patients. They don't show any ill or bad emotions on their faces and it shows that they want to do this for us. I feel respect for them because they give me so much kindness. (A grandmother, Sikh)

Most women felt that respect was mutual, because it is inherent in human nature to give respect when it is received. This woman described that when health professionals bestowed respect on her, respect was automatically invoked for the health professional:

> I think it is very mutual. If I don't respect them I don't expect them to respect me. Regardless of whether they are a doctor or a nurse and the patient, we're all human. They give us the regard and attention and care as patients. They don't show any ill or bad emotions on their faces and it shows that they want to do this for us. Things like giving juice, water, warm blankets, and attention. It makes it easier for us as patients. (A retired mother with grown children, Muslim)

### Consequences of Respect for South Asian Immigrant Women

Most South Asian immigrant women experienced feelings of happiness, compassion, safety, worthiness, being acknowledged, being valued, and a shared

humanity with health professionals. Women described these feelings as consequences of the respect bestowed by health professionals within health professional–client relationships. Participants felt that when health professionals genuinely greeted them and acknowledged their existence by giving them attention during their interactions in the health professional–client relationship, health professionals valued the women's humanity along with their individuality as a woman, regardless of the cancer condition.

For most participants, it was important that health professionals respected their South Asian ethnicity, age, gender, and worth as a person, regardless of women's ability to speak English or to express themselves clearly in English. Women described that the health professional's ability to create respect indicated that he or she regarded her as an individual with experience, a perspective, and a social identity. This woman's statement "I could show them who I am" clearly illustrated that she was her own person with her own personal experiences, which demanded respect in itself:

> I couldn't express myself clearly and I wasn't sure that I understood the answer as well. There wouldn't be a difference between the Canadian woman and the immigrant women. Only thing is the language, we don't have the ability to express ourselves as the Canadian woman can, you know it is little bit difficult and it is a challenge. My mother tongue, in my language it is easier for me to express myself when I want to talk about my feelings and to earn people's respect, it is very easy for me. Especially in my life it has happened to me this way many times that I could earn people's respect. I could earn their respect very easily, because I could show them who I am in my own language. It is a little difficult here to tell them; perhaps just sometimes in different situations it is very

> important. I could sometimes easily explain in my language, it is very easy in my own language. Sometimes I have to talk with the nurse after I talk with the doctor, because she is a woman and she understands more. (A mother with young children, Muslim)

By providing respect, health professionals valued South Asian immigrant women's personal experiences of anxiety, fear, and loss in the cancer journey. Participants shared that health professionals' capacity to create respect helped to alleviate these emotions. They described that most health professionals went beyond the routine of providing cancer care within health professional–client relationships when they acknowledged South Asian immigrant women as human beings. This woman shares her experience of being regarded as a person:

> When I go into the clinic, they give me a gown and I go and change room behind the curtains. These little things make a lot of difference because I am already ill, and my heart is already hurting, so these little things make my heart feel better. It makes me feel joyful and happier inside when I am spoken to as a human being and respected as a human being. It makes me feel better about myself. When the nurses talk to me in a respectful way, it shows that I am a woman and a human being as well. I want to be regarded as a person. (A retired mother, Hindu)

Women experienced feelings of worthiness when health professionals' respected each South Asian immigrant woman as her own person, regardless of whether she could express herself in English or even wanted to. This following excerpt indicated that South Asian immigrant women could be respected for themselves, regardless of their ability to express themselves in English:

> Usually I understand English but when there is a lot of pain involved then I don't want to speak in English at all. I just don't want to speak or I do not want to think so much. If they speak to me slowly in English I understand them. (A retired mother, Sikh)

South Asian immigrant women indicated that by creating respect within the health professional–client relationship, health professionals were able to value a woman's humanity and social identity as an individual, regardless of her South Asian descent, age, and gender, or cancer condition. Health professionals' perspectives and approach indicated that they respected South Asian immigrant women as individuals without making assumptions and stereotyping them when providing cancer care. South Asian immigrant women's perceptions of factors that influenced their experiences in the clinical setting are discussed next.

### Women's Perceptions of Factors in the Clinical Setting that Influence Their Experience of Respect

The two clinical settings from which the participants were recruited were similar in terms of the physical environment, procedures, and structure; the information provided in relation to cancer and its treatments, and the types of cancer care services that were provided. These similarities were reflected in women's stories of respect within health professional–client relationships in the clinical setting. Women described positive experiences of respect at both clinical settings. Most women shared their experiences and made suggestions about the factors that had enhanced and those that had inhibited respect within this clinical context.

Health professional demographics played a large part at the cancer agency where South Asian immigrant women, among other diverse groups of clients, were served by

mainly Euro-Canadian health professionals. The physical environment and structuring of the procedures at the clinical setting were seen as facilitating respect. Women felt that the clinical setting and the structure allowed them to share their experiences with other women who were going through similar experiences. Most participants shared that health professionals were able to provide respectful care regardless of the busy clinical settings. They described that they never had to wait for too long despite the busyness of the cancer treatment clinics, as illustrated by this woman:

> You know even if they are busy I never had to wait for more than ten minutes, never, at the most ten minutes if they are busy, but normally you know the nurses are busy, but they were there in ten minutes and took me inside and started the chemotherapy treatments. There were always nurses around in the clinic. (A retired mother with grown children, Muslim)

Communication and language, staff characteristics, and the use of interpreters were experienced as either enhancing or hindering respect, depending on the policy and guideline constraints under which health professionals had to orchestrate their work day. South Asian immigrant women shared their experiences of respectful exchanges with health professionals when they communicated valuable information in a manner that facilitated their understanding of the cancer condition.

### *Communication and Language*

Findings showed that South Asian immigrant women's experiences were enhanced by health professionals' way of talking while providing cancer-related information. However the women recognized that health professionals' communication styles and language differed because of their personal way of being and make-up, which

influenced their approach to the health professional–client relationship. Most shared that communication styles and the terminology used by health professionals while providing explanations either increased or decreased clients' comprehension of their condition and treatments. Some women described that health professionals used understandable language, and this type of communication style and information delivery helped put them at ease during these vulnerable times. These women felt that the health professional's approach to the relationship at this time enhanced respect:

> I'm saying that this cancer information was very valuable and they knew what I needed. I did not have to ask very much. When you don't know what you need and you don't know what to ask for. They knew what to give me regarding my cancer and the way that they gave me the information it was helpful for me, they gave me this information and they knew what I needed. (A mother with young children, Muslim)

In contrast, other women felt that health professionals' way of talking and engaging with them during the interactions either closed the door or opened it to further interactions. This woman felt that this physician closed the door when he used medical terminology while "talking with her" about her illness:

> I told him the name and he said I don't know what you are talking about, but see his communication style made it sound not as respectful to me. He was talking in his medical terms and I didn't know the right word at the time. He said I haven't heard that word before. You know it can happen that sometimes you think he doesn't want to pay attention, but it is his terminology that he uses. You know they go in medical terms and sometimes you know it is misjudgement too, but I

never felt that there was no barrier between caste and whatever. (A retired grandmother, Hindu)

This woman felt that the health professional was not conscious of his communication strategy, which decreased her ability to comprehend the information. For most women, health professionals' behaviour and courteous manner in their approach helped to increase their understanding of their cancer condition and its related treatments. Women shared that most health professionals took the time to engage with them by attending to their informational needs regardless of their busy schedules. These women shared that it was not only the quantity of information that was provided but also the quality of the delivery; a communication style that enhanced women's experiences of respect is illustrated by this woman:

> You know sometimes the health professionals at the cancer agency, at the clinic, are very busy and do not have time because they are always running for this and that. But you know, they always fitted me in and sat and explained to me, especially when I was getting chemotherapy, they would talk to me nicely. It is the way they talked and looked at me. (A mother with grown children, Christian)

South Asian immigrant women suggested that communicating and receiving information about a cancer condition is difficult under any circumstances for both health professionals and clients; however, the health professional's approach to the relationship and his or her way of talking could either enhance respect or create barriers within the health professional–client relationship.

*Staff Characteristics*

Staff characteristics such as ethnicity and gender had a large impact on how South Asian immigrant women experienced respect within health professional–client relationships. Most women were able to identify with South Asian female health professionals from their own culture and ethnicity and were able to converse with them in their own language. These experiences with South Asian female health professionals helped to create a safe environment for women because they identified with health professionals who were female and recognized their cultural understanding of respect. When non–English-speaking women were in health care relations with South Asian female health professionals, they experienced higher comfort levels because the health professionals were female and South Asian. Most women indicated that this was an enhancing factor of respect:

> Oh she was very good with us. It felt very comfortable even though she was Punjabi speaking, because she was a Punjabi lady, but she was very good and made me feel comfortable, because she was a woman doctor. Even though I speak Hindi not Punjabi, it still felt good for me. (A grandmother, Hindu)

Health professionals who spoke the women's language and were able to listen to their stories firsthand without interpreters facilitated respect within the health professional–client relationship. This woman shared that she felt comfortable and respected when she was able to speak directly to her medical oncologist about her suffering and pain related to cancer and its treatments:

> The lady doctor who is Indian, she explained all the medication and how to take them and when to take them. I didn't have any problem. And for example when

> the doctor speaks in Hindi and she knows that I don't speak English so she speaks to me in Hindi. And she tells me what is wrong with me. (A retired mother, Hindu)

South Asian male or female health professionals were described as members of women's community who understood the cultural aspects and etiquettes of greeting and bestowing respect. Women experienced feelings of respect when South Asian health professionals addressed them as "aunty" and were able to speak to them in their own language. These health professional client relationships further enhanced respect and development of the relationship for most non–English-speaking women, as described by this woman:

> When I feel really dizzy, they ask me whether I want to see the doctor and if I am doing all right or not. They are all very nice especially the East Indian nurse who is there. She speaks to me in my own language and is very kind and calls me "aunty" and I feel good and it is respectful 'cause she calls me "aunty," whereas the other nurses call me by my name which is the way that the other nurses and therapists call me because it is the normal way to do for them. They all respect me otherwise by the things that they do. (A mother with married children, Sikh)

While doing participant observations, I witnessed young South Asian male radiation therapists and female chemotherapy nurses conversing with older South Asian immigrant women during their cancer treatments. The women were able to ask questions about their cancer-related pain and side effects while going through the treatments, although interpreters were not present. This was important for these women. Most South Asian immigrant women experienced respect when male or female health professionals

conversed with them in their own language and provided detailed information in relation to the cancer condition and its treatments.

*Interpreters*

Interpreters from an outside source were used to provide information for non–English-speaking women during their initial and posttreatment clinical visits. However, interpreters were not readily available for women during their ongoing cancer-related treatments, unless it was deemed necessary by health professionals. Most women experienced respect during interactions with interpreters, as the interpreters provided information and explanations about treatments as illustrated.

> They asked me on the phone if I spoke English or not before I went in to the cancer clinic. Then they have an interpreter who spoke Punjabi for me. They talked to me very nicely and talked to me politely. There was a Punjabi nurse who talked to me the first time and explained everything to me and told me all that they are going to do. My daughter was there at that time and they told me everything in Hindi. I think it is very respectful that they know my feelings from my heart about how I feel because a patient cannot say what they feel from the heart if they don't understand or cannot express it in their own language. So it was very respectful that they brought somebody who could understand and through whom I could understand what they're saying. (A mother with married children, Sikh)

This woman's story indicates that health professionals made assumptions about what language most South Asian immigrant women spoke. Women felt that health professionals were unaware that the Indian language comprises different dialects spoken

by subgroups of South Asian immigrant women. Some women who spoke Hindi, for example, were provided with Punjabi speaking interpreters, as illustrated by this woman:

> In the beginning when I began my chemotherapy there was an Indian woman there who spoke Hindi and explained everything to me, that was the first chemotherapy. I did not have any problems because this interpreter spoke very clear Hindi. You know some of the Punjabi women speak Hindi very well, but some only speak Punjabi, like the nurse who gave me chemotherapy the other day, she only spoke Punjabi. (A widow with children and grandchildren in her home country, Hindu)

Some women shared that although interpreters facilitated their understanding of the cancer condition and its related treatments, a lack of written educational material in their languages created a barrier to a more complete comprehension of the side effects and symptoms related to chemotherapy and radiation treatments. During the participant observations, health professionals shared that provision of language-specific written educational material would enhance South Asian immigrant women's understanding. They shared that South Asian immigrant women would be able to read this material at their leisure together with their families. In addition, health professionals shared that some key information might not be fully captured by South Asian immigrant women during clinical visits because the women might already be overloaded with verbal information.

### *Sharing Experiences*

Most women felt that sharing their personal cancer experiences with other women who were going through chemotherapy and radiation treatments was another factor that

enhanced respect. These women felt respected when health professionals allowed them the opportunity to interact with others who were going through similar experiences in the outpatient follow-up clinical setting at the cancer agency. Being able to share stories with other women who were going through similar experiences gave women a sense of support and a feeling of community while going through treatments:

> I was fine with having more than one person. Actually, it was better than being alone because we could talk sometimes with the others. I think it is better than being alone. It takes about forty-five minutes to one hour so it is good to have someone to talk to. They talk about their experiences. It wasn't so bad. You know the whole environment there. Especially in the beginning I like to meet more people with the same problem you know. I have to sit there the same as everybody else does as well, you have to, but we can share the pain and stories. I do not find it disrespectful; I think it is better for us, especially in the beginning. (A widow with grandchildren, Muslim)

Women found themselves sharing their most challenging experiences, such as hair loss, purchasing a wig, and coping with the side effects of treatments. Some women described their day at the chemotherapy clinic as being similar to visiting with friends:

> Oh it was OK, because all three or four of us we all talk together and with each other about our experiences and we shared and it was OK. The nurses they offered us water and juice drinks, what ever we want. Well, it was that they had the same experience, for example when my hair started to fall off when I started losing my hair and how it was and where to get the wig. And other stories that they had gone through, and we shared where we should go, what they felt.

(A grandmother, Hindu)

These experiences facilitated respect for most women. Being a part of the cancer community provided support for women journeying through cancer, especially initially, when they had a lot of questions. Women felt respected and acknowledged regardless of their ethnicity, gender, and cancer condition while sharing these experiences. They felt that health professionals respected women's need to share their relational experiences of the cancer journey. This woman described her experiences of sharing while in the chemotherapy clinical setting:

> I was happy inside in a way because I was going through that bad disease, but I felt comfortable, if I have to somebody to talk to. Besides I am not alone because there are other people in the same boat and they [are] maybe worse than I am. You know you cry when it happens, but it is nice to be there with others in the chemotherapy room and share all these experiences with others who are feeling it too, you know. It did not matter if there were eight or ten people in the clinic, all talked to each other, even though it is a small room, it is alright, cause it is support to talk to others. (A retired mother with grown children, Muslim)

Most women experienced that the clinic's physical structure and environment, despite the overcrowded chemotherapy and radiation treatment clinics, provided a facilitative atmosphere for sharing with other women who were going through similar experiences. Women felt that health professionals understood their need for sharing and respected them without making assumptions that South Asian immigrant women might not want to share because they did not speak English.

### *Making Assumptions*

Although the focus of this study was respect, I asked women to describe their experiences of a lack of respect during their health professional–client relationships at the outpatient follow-up clinical setting at the cancer agency. This form of questioning allowed women to describe their feelings of disrespect and to reflect on their experiences of respect. Women's stories of negative experiences helped to clarify their understanding of respect within health professional–client relationships.

South Asian immigrant women did not share any stories of a lack of respect within their health professional–client relationships. They felt that health professionals had not disrespected them as South Asian immigrant women. However some women felt that health professionals had some preconceived assumptions and lumped all South Asian immigrant women together rather than providing individualized cancer care. During the participant observation, I witnessed an exchange between a health professional and a non–English-speaking woman with her family who spoke English. The health professional wanted me to translate cancer-related information for the patient, who was of the same ethnicity as I am, even though this woman had a family member who spoke English. The health professional assumed that neither this woman nor her family member spoke English.

My observation was evidence that some women's clinical experiences fell short of their expectations. Some women described experiences of being stereotyped by health professionals as being non–English-speaking South Asian immigrant women. Their stories indicated that health professionals assumed that most South Asian immigrant women did not speak English; therefore, they directed their conversation at the interpreter

rather than to women. This woman described her experiences when the physician assumed that her daughter, who had accompanied her, did not speak English, as she did not speak English:

> When I went with my daughter, they did not ask her if she spoke English, they just assumed she did not speak English just like me. My daughter spoke English and she told them when they kept talking to the interpreter who told me what they were saying. Well I think they have to think of one situation as different from others, such as one woman to another woman, for example if someone comes to me in the kind of work that I do, I don't look at everybody as the same, at the same level. I look at them differently, not in the same way. I look at them individually. As soon as one patient is gone you should get to the new one with a new mind, because I may speak English whereas they do not. (A retired mother with grown children, Hindu)

Some women felt that health professionals' assumptions created barriers and did not allow women to feel respected during their clinical visits. They suggested that health professionals should offer a more individualized approach and ask women about their ability to speak English, regardless of the women's age, gender, or ethnicity. Women felt that this approach to the health professional–client relationship would reduce assumptions and stereotyping and increase respect.

### My Perceptions of the Factors that Influence Respect

Participant observations illustrated how the physical environment of the clinical setting increased respect when South Asian immigrant women waited in the common lounge before going into the examination room to change into their gowns behind closed

doors. The structure and physical environment of the clinical settings addressed South Asian immigrant women's need for privacy and respect when health professionals provided gowns to women before they entered the examination rooms. This allowed women to wait for the oncologist in the examination room instead of in the common lounge with others. As evidenced earlier in this dissertation, privacy denoted respect for South Asian immigrant women, because they felt shy and embarrassed.

My observations also illustrate that the limited number of South Asian health professionals at the clinics placed an extra burden on the nonminority health professionals' already busy schedules and time constraints when they had to provide information for women through interpreters. This was evident when a chemotherapy nurse, who was already providing cancer treatment for eight other cancer clients, had to provide information related to the new chemotherapy treatment for a client who was part of a clinical drug trial. This chemotherapy nurse had to rearrange her other work to make time for this client and her family members to translate a lengthy procedure before beginning this particular treatment. This client and her family needed to understand the duration of the clinical drug trial and its procedures, along with its side effects. The written educational information provided to this woman and her family was in English, however, thereby limiting their ability to understand further the complex information at their own leisure. From these observations, it is evident that a language barrier between "mainstream" health professionals and South Asian immigrant women decreased health professionals' ability to communicate about complex cancer information and related treatments.

Participant observations illustrated that the busy and crowded spaces in the chemotherapy and radiation treatment clinics were not an inhibiting factor. Although there were usually a fair number of people at each unit, clients usually waited their turns patiently while working on puzzles, knitting with the yarn that was provided, or reading the magazines, whereas clients in the chemotherapy clinic were busy discussing their chemotherapy experiences or just dozing off during the treatments while family members hovered over them. This observation was parallel to South Asian immigrant women's perceptions that the crowded spaces in both the settings did not hinder respect because it was the health professional's approach that made a difference. Participants shared that they would make allowances for busy health professionals because a busy clinical setting was an expectation of the outpatient follow-up clinical settings at the cancer agency.

I observed that exchanges between health professionals and clients in both settings created respect for all the clients, regardless of their ethnicity and type of cancer. Most of the health professionals took time and treated clients with respect by paying attention to them while providing information and cancer treatments. Health professionals generally sat at the same level as the clients when talking to them about important details of the cancer condition and its related treatments. These observations showed that most health professionals were aware of the agency's policy pertaining to providing patient-centred care. I also observed that both male and female South Asian health professionals were able to communicate openly with South Asian immigrant women and their family members, which enhanced women's respect and increased their understanding of the cancer treatment process. Female South Asian health professionals

were able to display respect by touching South Asian immigrant women appropriately and addressing them as "aunty" instead of by their given name.

These participant observation illustrations coincide with South Asian immigrant women's perceptions of factors that influenced their experiences of respect within the health professional–client relationships. They confirmed South Asian immigrant women's stories of health professionals' approach and way of being creating respect, regardless of the inhibiting structural and organizational factors that could create barriers to positive experiences of respect.

## Summary of the Findings

The purpose of this study was to examine South Asian immigrant women's experiences and perceptions of respect within health professional–client relationships. The results showed that for South Asian immigrant women, respect meant being acknowledged as human beings through being greeted, being treated as equals, and being valued for their individuality. The health professional's approach, which was identified as his or her personal way of being, inclusive of his or her courteous manner and professional behavior, portrayed respect within health professional–client relationships. This approach also included his or her way of talking while providing information, and attention to women's personal needs in relation to their cancer condition and related treatments.

South Asian immigrant women described touch, privacy, compassion, and reciprocity as their expectations of respect within health professional–client relationships. Women felt their heritage played a large part in the expectations and personal meanings of respect that they brought to their health care relationships. These personal meanings

were informed by both individual and societal practices, beliefs, and values that were ingrained within South Asian immigrant women's culture and ethnicity. The appraisal of respect for South Asian immigrant women within health professional–client relationships was embedded within their individual frame of reference to relationships. Factors that acted as facilitators or inhibitors for creating respect within health professional–client relationships within the outpatient follow-up clinical setting were identified. A discussion of these findings will provide greater insight into South Asian immigrant women's perceptions of respect with health professionals when orchestrated at the micro level of interactions within the structures of the meso/macro level of the health care agency.

# CHAPTER FIVE

# DISCUSSION

The study illuminated South Asian immigrant women's experiences and their perceptions of respect within health professional–client relationships as they journeyed through cancer. An examination of the data provided a window into how South Asian immigrant women's cultural worldview, gender, and previous health care experiences influenced how they experienced respect in the context of the outpatient follow-up clinical setting at the cancer agency. Their expectations of respect within a relationship with health professionals in light of their heritage, personal experiences, and standpoint provided greater insight into how the women orchestrated their daily lives. In this chapter, I will discuss significant findings in light of relevant research and present the strengths and limitations of the study.

It is not my intention that the preliminary findings of this study be generalized to other immigrant groups or to other clinical contexts. These findings revealed the complex factors that were at play within the health professional–client relationship when predominantly English-speaking health professionals provided health care to diverse ethnic populations. Until now, no researchers have examined respect directly with South Asian immigrant women within health professional–client relationships in a cancer agency health care setting. Browne (1993, 1995, 1997), however, has examined respect with First Nation's persons' health care experiences in clinical settings, which will be discussed along with other studies that have identified respect as an essential aspect of providing health care for the immigrant and non-immigrant populations with or without cancer in various health care settings.

## South Asian Immigrant Women's Perception of Respect

This study provided the client's perspective of respect within health professional–client relationships in the outpatient follow-up clinical setting at the cancer agency. The findings offer insight into how South Asian immigrant women wanted to be respected and how they viewed respect as being bestowed through the health professional's "way of being." Health professionals' capacity to respect women during clinical interactions, thereby acknowledging and valuing them as human beings, helped to illustrate the central theme of the findings: "who I am." This theme was consistent in women's stories of feeling acknowledged, accepted, attended to, and recognized as individuals with a social identity, a standpoint.

The findings of this study indicated that a level of communication that respects the other by acknowledging his or her existence is possible during clinical interactions. Women's positive feelings of respect led to their feeling accepted and acknowledged as "persons" during their agency visits, regardless of their ethnicity, cancer condition, or gender. Being recognized as persons and being valued as individuals with identities and experiential stories to share about their lives in the midst of their cancer journeys became the central essence of respect for the South Asian immigrant women in this study. Hilton et al. (2001), in their study with South Asian immigrant women in Canada, confirmed that respect for women's need to practice their traditional home remedies provided a way to "maintain and preserve their cultural heritage and identity as a South Asian woman" (p. 558). These authors stated that South Asian immigrant women felt respected when they were able to incorporate their traditional practices into their daily lives. Kirkham (2003) reported how connected care was marked by respectful interpersonal connections

during clinical interactions, which created an understanding of the illness experience from the patient's perspective and a holistic grasp of the patient's health care needs from the health professional's perspective. She further added that the patient's social identity was influenced by their interpretive lenses, which were informed by societal, experiential, and personal beliefs and values.

### Respect from a First Nation's Perspective

Browne (1995), in her study on respect involving Cree-Ojibway First Nations persons in a hospital setting, described parallel findings when health professionals genuinely attempted to understand patients' unique situations and acknowledged them as equals who were worthy of being respected. In addition, informants described the "values of equal status, inherent worth, and acceptance as being essential to respect" (p. 101), especially when they were hospitalized in a foreign clinical environment. Browne found that acknowledging a fellow human being regardless of his or her position in society, gender, age, or health status is an inherent quality that values the other's inherent worth as a human being.

Most immigrant population and gender-focused studies have recommended that respect be bestowed through the provision of equitable health care for all people regardless of their culture, ethnicity, gender, or age (Anderson, 1998; Browne & Fiske, 2001; Kirkham, 2003); however, Vydelingum (2005) found that nurses operated under a false consciousness of equity when they treated everyone the same and reported that these "nurses were actually providing unequal health care" (p. 260.), as everyone is not the same, because each person has individual needs in light of his or her life experiences and beliefs. Robinson and Elkan (1996) reiterate that horizontal equity, the idea of

treating everyone equally, might lead to inequity, because everyone is not equal or the same. These previous authors suggested that vertical equity, which suggests contradictory ideals by professing to provide unequal but appropriate care, might be more suitable, thereby meriting an individualized or a person-centered approach.

Browne (1995) identified health professionals' acceptance of others as individuals and their willingness to listen actively when providing health care in the clinical health care setting as specific components of respect. Similar to Browne's findings, women in this study related that health professionals' way of talking when providing cancer care during treatments, along with their attentiveness during the chemotherapy and radiation treatment sessions, were essential to respect, because this behaviour valued their humanness within the health professional–client relationship. Shared humanity was deemed as respect in cancer care, because of the women's fear and their prognosis related to their cancer condition.

Health professionals' approach and way of being at the beginning of the relationship helped to foster an open and trusting health professional–client relationship within which South Asian immigrant women were able to share their innermost fears and stories of their suffering. Informants in Browne's (1995) study described that a "link between [health care] providers' attitudes toward them as First Nations people and the incidence of respectful clinical interactions created feelings of equality and worthiness" (p. 101). Health care providers' attempts to provide adequate explanations to patients during clinical interactions in Browne's study resonate with findings of health professionals' way of talking while providing detailed explanations about cancer. In addition, these attempts show how informational support played a key part in helping to

create respect within health professional–client relationships. This characteristic played a role in the health professionals' providing understandable information and determining the patient's ability to make decisions related to cancer and its treatments.

In her second paper, Browne (1997) reported findings from the participant observations data from the aforementioned study, and the health care providers' comments and observations. Browne described health care providers' attempts to acknowledge and accept the patients' cultural orientation as being respectful. In her study, health care providers conveyed respect by taking the time to listen to patients' unique cultural or social perspectives in regards to telling stories of their health care experiences and health status.

Findings from Browne's (1995, 1997) studies show that respectful health professional–client relationships are possible during clinical interactions in the health care setting. The South Asian immigrant women in our study validated these findings when health professionals paid attention to them and listened attentively during clinical interactions while providing cancer-related treatment, thereby acknowledging and respecting the women's unique personhood, rather than seeing only South Asian immigrant women with a cancer condition.

Respect as an Outcome of Cancer Care with South Asian Immigrant Women

Although there have been no studies conducted directly with South Asian immigrant men or women who have cancer conditions concerning respect as a phenomenon, several researchers have examined women with breast and cervical cancers and their experiences. Bottorff, Johnson, et al. (1998), in a study of South Asian women's beliefs related to breast cancer, highlighted the need to respect and recognize the beliefs

concerning a woman's calling and her modesty related to how she presents herself in society, and how she is to act in society and within the community. According to Bottorff and colleagues, these beliefs influenced every aspect of a woman's life and, ultimately, provided a lens through which women viewed breast health practices in their personal lives. Part of providing respectful health care for non–English-speaking South Asian immigrant women was the provision of interpreters during their health care visits to the women's clinic for follow-up visits related to further screening for cervical cancer (Bottorff, Balneaves, et al., 2001; Singh, 2002). However, these authors noted that written educational material in the women's own language was not always available, especially for all the subgroups within the South Asian immigrant women population.

Other studies with South Asian immigrant women and their experiences with breast and cervical cancer have reiterated the need to respect and to be sensitive to South Asian immigrant women's needs for female South Asian or non–South Asian health professionals, because of the women's modesty and fear of cancer and its relation to stigma within the community (Bottorff, Balneaves, et al., 2001; Bottorff, Johnson, et al., 1998; Choudhry, Srivastava, & Fitch, 1998).

These studies confirm the findings that South Asian immigrant women identified respect as part of the health professional's approach or way of being when they made attempts to make women feel more comfortable and at ease because of their shyness and modesty. This was especially true when female South Asian or non–South Asian health professionals provided dignified care during examinations and cancer-related treatments. However, the danger of writing about South Asian immigrant women's practices related to shyness, modesty, and their preference for female health professionals over male

within health professional–client relationships at the clinical setting might unintentionally reproduce essentialized notions about how South Asian immigrant women with cancer conditions want to, or need to be treated (Lynam, Henderson, et al., 2003; McCormick, Kirkham, & Hayes, 1998). Evidence from other studies suggests the need for women-centered care when providing cancer-related screening such as Pap testing and breast examinations (Bottorff, Balneaves, et al., 2001; Grewal, Bottorff, & Balneaves, 2004; Singh, 2002). However, the development of services that fully embody the components of women-centered care might sometimes be hampered by such structures in the health care system (Bottorff, Balneaves, et al., 2001; Fitch, Greenberg, et al., 1998).

## South Asian Immigrant Women in Other Health Care Settings

Descriptive findings that highlight only immigrant women's health care practices can lead to the essentializing and further stereotyping of the particular immigrant group's cultural practices and beliefs that inform their health care practices. These descriptive findings tend to serve as a distraction from the context of the clinical setting within the larger social and institutional context. Other researchers who have explored South Asian immigrant women and health care in other clinical settings have also highlighted the danger in essentializing explanations about a subgroup's health care practices (Johnson, et al., 2004; Kirkham, 2003; Lynam, Henderson, et al., 2003). Although it was important to analyse the findings of respect in my study from the South Asian immigrant women's context and their life experiences, which were influenced by the women's heritage, it was just as important to remember that individual interactions were embedded within the larger social and institutional context of the clinical setting. This mode of critical analysis helped to de-essentialize South Asian immigrant women's experiences at the cancer

agency setting and enhanced their individuality within the health professional–client relationship in the larger social clinical setting (Browne, 2003). Ahmad (1993) and (Vydelingum, 2000) have suggested that adopting a familiar checklist/cookbook pattern, which includes general guidelines on a wide range of religious and cultural practices and rituals, negates the whole person, who has individual everyday experiences that she brings to the health professional–client relationship, including her South Asian immigrant worldview (D. E. Smith, 1987).

A number of studies have indicated that "culturally sensitive" or "culturally safe" care should be provided to immigrant populations (Anderson, Dyck, & Lynam, 1997; Bottorff, Johnson, et al., 1998; Browne, 2001; Kirkham, 2003; Meleis, 1996; Perry, Lynam, & Anderson, 2005; Smye & Browne, 2003). Findings in these studies have indicated that practicing culturally sensitive and culturally safe care can help to provide respectful health care to those clients who are different from the majority of the population that accesses health care. On the other hand, Stevens (1995) has suggested that an ethno-specific approach that focuses on describing the characteristics, beliefs, and behaviours of a specific group does not allow us to take the diversity within the group into account.

What does provision of culturally sensitive or safe health care look like for the health professional who is not aware of the particular immigrant group's cultural values, historical background, political, societal, or personal experiences? Gibbs (2005) has questioned whether cultural safety can realistically be taught to nursing students, because at face value, integrating cultural safety is positive, but with the limited time allocated to teach some subjects, it might be unrealistic to integrate cultural safety, especially because

of the shifting and elusive nature of the concept itself. In addition, Gibbs suggested that the key to cultural safety lies in the attitude of the student, because the student's attitude is something that has to come from within that person, which includes a change in his or her way of thinking.

Findings from this study confirmed that the health professionals' approach, which included their way of being and their make-up, helped to create respect for women when health professionals acknowledged South Asian immigrant women by being courteous and professional in their approach. Health professionals' ability to communicate respect through genuine and spontaneous greetings and by interacting with women on an individualized basis at the beginning of the health professional–client relationship helped to give it a "person-centered" approach, whereby identity was more important than ethnicity. Kirkham, Pesut, Meyerhoff, and Sawatsky (2004), in their study on spiritual care-giving from the nurses' and chaplains' perspectives, suggested that we ought to acknowledge individual human beings' capacity to make contact with each other through humanitarian gestures, such as being present, listening, respecting, and loving, when initiating health professional–client relationships.

The findings in this study indicated that South Asian immigrant women were pleasantly surprised when health professionals at the cancer agency clinical setting were attentive to their physical, emotional, and informational needs. These new health care–related experiences were different from their previous negative ones with other health professionals at different health care institutions in Canada or in their country of origin. For example, one participant voiced her experience of being brushed off by a health professional during an emergency room visit, when the health professional did not take

time to provide clear explanations. Related research with South Asian immigrant women has found that health care providers neglected women's health care needs and brushed them off because the women did not always ask questions (Bottorff, Balneaves, et al., 2001; Singh, 2002).

Johnson et al., (2004), in their study about "othering" in health care services with South Asian immigrant women, noted the need for values such as equality and respect for diversity within the health care setting; however, these notions might sometimes be used in ways that obscure the very real barriers and disadvantages that most immigrants face in accessing health care and adjusting to life in Canada. Vydelingum (2005) reported that by seeing only the differences within the "other" cultures, health professionals' tended to practice a reductionist approach that allowed the nurses to view immigrant women "as a series of 'dos' and 'don'ts'" (p. 29) rather than as people with their own identity. Vydelingum asserted that valuing and respecting South Asian immigrant patients and their family members regarding hospital visiting hour policies could have been achieved through the influence of South Asian care assistants within the hospital setting.

Johnson et al. (2004) described how some "women simply wanted health care professionals to be nice, to listen to them, to be polite and respectful" (p. 265), whereas others wanted to "to be treated like the 'White lady' in the next bed" (p. 265). Research conducted in other health care institutions reported that immigrant women's repeated calls for assistance went unanswered and unacknowledged, whereas time was given to the Caucasian patient in the next bed (Lynam, Henderson, et al., 2003; Spitzer, 2004). These differences in how health care was provided and perceived by clients in other health care settings might be due to factors such as the institution's budgetary restrictions,

nurses' work overload, time-constraining interactions because of language barriers (Lynam, Henderson, et al., 2003), or institutional and societal forms of discrimination within the health care system (Brown, Carroll, Boon, & Marmoreo, 2002; Reimer-Kirkham, 2000). Social, political, economic, and institutional factors enmeshed within the organizational structuring of the health care system play a large part in how care is provided within health care institutions, including the clinical setting at the cancer agency.

Language barriers were constantly cited as one of the biggest challenges of intercultural health care that created difficulties when health professionals needed to communicate important health-related information to immigrants (Bottorff, Balneaves, et al., 2001; Hayes, 1995; Kirkham, 2003; Lynam, Henderson, et al., 2003; Perry, Lynam, & Anderson, 2004). Kirkham (2003) observed that there seemed to be a widespread acceptance of the lack of available interpretive services, which suggested a preference for English and an expectation of linguistic assimilation by health professionals, who rarely used the interpretive services that were available. Perry and colleagues (2004) reported that the staff was unable to "know the patient" and be able to attend to the layers of meanings of the illness experiences in the absence of a shared language and direct communication with the patient and their families. Hayes (1995), on the other hand, found that some health institutions provided interpreters during standard working hours only. In addition, the findings revealed a lack of insight on the part of the health professionals concerning the range of South Asian languages spoken when these professionals recruited Punjabi-speaking interpreters for Bengali-speaking Muslim women. This was paralleled in these findings, in which Punjabi-speaking nurses or

interpreters were limited in their translation skills because they did not speak Hindi, Urdu or Tamil. Perry and colleagues (2004) reported that when families are unable to interact and communicate with the health care team to share the illness experience within respectful and nurturing health care relations, the likelihood that families will, indeed, become vulnerable increases. In addition, this vulnerability is due to a lack of information and support that meet the needs of the identified patient and his or her family. The problem of communication with non–English-speaking patients with the use of interpreters is characterised by half-hearted stop-gap measures between the health professional and the interpreter that do not allow for a fully comprehensive dialogue to be created (Lynam et al., 2003).

It is crucial to consider contextual factors, such as gender, social environment, culture, and structuring of the health care system and the clinical setting, which will influence how most South Asian immigrant women locate themselves in light of their standpoint within the health professional–client relationship. Anderson and Kirkham (1998) have suggested that in the present discourse of multiculturalism, ethnicity, visible minority status, and the like, inherent social relations mask the processes that determine people's experiences and create stereotypes, therefore extending into what is assumed to be people's beliefs and practices concerning health and illness. Das Gupta (1994) directs us to how multiculturalism policies and practice of multiculturalism in Canada has been successful in reproducing oppressive gender, race, and class relations and ideologies. Das Gupta (1994) further suggests that the reproduction of these factors have been socially organized by a complex mesh of state practices of multiculturalism which further facilitates the divisions in the community. Kirkham (2003) suggested that researchers

conducting studies with immigrant populations have to be critical in their analysis, examine the "assumptions of respectful and equitable care underlying our health care systems," and "connect the dynamics of nurse-patient encounters to broader social issues" (p.776).

## Health Care Relations and Immigrant Women with Cancer

Studies with other immigrant populations and cancer indicated parallel accounts of respect when health professionals provided care for clients journeying through cancer. Findings from these studies show clients with cancer experiencing respect when they were treated as a person, a whole person, and not just a number who needed cancer-related treatments in the clinical setting (Fitch, Greenberg, et al., 1998; Liu, Mok, & Wong, 2005; O'Baugh, Wilkes, Luke, & George, 2003; Thorne, Harris, et al.,1999). Liu and colleagues explored the concept of caring in nursing with cancer clients. They described that the behaviour and attitudes of nurses left an impression of respect in the minds of the clients, which was valued by the clients, who had to make difficult decisions about their life. Their findings indicated that nurses' greetings and smiles portrayed caring attitudes toward patients; as well, greeting the other with a smile and acknowledging his or her presence at the initial contact created respect in the relationship. These findings confirmed South Asian immigrant women's descriptions of health professionals' making time to greet them genuinely at each visit regardless of how busy they were at the time. Health care providers' professional behaviour and manner when delivering cancer and treatment-related information created informational support, helped clients cope with and adjust to their cancer condition, and decreased their feelings of powerlessness (Liu et al., 2005). South Asian immigrant women in this study defined

*attitude* as the health professionals' way of being, which included their professional behaviour and personal courteous manner in their approach, which fostered respect within health professional–client relationships.

In addition, Liu et al. (2005) emphasized that it was important for cancer clients to understand the explanations and suggestions of health professionals who were communicating cancer-related information, because this contributed to the establishment of a trusting nurse-patient relationship. This open communication approach was identified as a characteristic of a supportive communication style that helped to demonstrate the health professional's sensitivity to the patient's psychosocial needs by creating a respectful partnership between the two (Liu et al., 2005; Mystakidou et al., 2004). Listening attentively, also identified as being present, was consistently found to be the most desired behavior and attitude in physician-patient relationship in cancer care research (Harris & Templeton, 2001; Liu et al., 2005; Richardson, 2004; Wright, Holcombe, & Salmon, 2004). Stanley (2002) has found that from a humanistic perspective, respect has been defined as a profound veneration of human dignity, honored consistently, demonstrably, and without exception.

Findings from other studies similarly shared that patients quickly developed friendships and created support groups with fellow patients by sharing cancer-related information and experiences (Brown, Carrol, Boon, & Marmoreo, 2002; Liu et al., 2005). Bottorff, Johnson, et al. (1998), in their study related to South Asian immigrant women's breast health practices, found that "South Asian women shared information with one another through stories" (p. 2083). These authors emphasized that stories of positive and respectful cancer care experiences will encourage other immigrant women's participation

in preventive breast and cervical cancer screening practices rather than reinforcing fears about cancer and its related treatments. Findings related to diversity in communication styles from studies that have explored physician-patient and nurse-patient relationships with cancer patients showed that health professionals were able to create positive, respectful environments by seeing the person, rather than the patient; in these instances, the patient felt respected and acknowledged, regardless of the biological diagnosis of cancer (Harris & Templeton, 2001; Jenkins & Fallowfield, 2002; Liu et al., 2005; Thorne et al., 2005; Wright et al., 2004). This person-focused form of providing cancer care was found to have the capacity to allow individuals to flourish because they were valued for their personal social identity. Findings in these studies illustrate how the complexities of providing cross-cultural health care services in a social clinical setting are generally heightened by a life-threatening cancer condition, especially as most immigrant women have multiple needs for information on cancer, its related treatments, and side effects when making decisions that will affect their immediate families in Canada and their extended families in their country of origin.

### Health Care Relations with Non-Immigrant Women with Cancer

Studies with non-immigrant women and cancer found that being acknowledged and respected as a whole person were perceived as being connected and accepted as a human being (Roberts, 2004; Thorne et al., 2005). Thorne et al. found that being known was evidence of a human connection in health care relationships, which thereby increased patients' well-being, an outcome of the dynamics of a positive, respectful health professional–client relationship. Being connected and respected were seen as a centrality of the physician-patient relationship in these studies. Aurora (2003) and Luoma and

Hakamies-Blomqvist (2004) showed that respectful care during treatments fostered hope for recovery and increased the patient's ability to function, thereby improving quality of life as well as prolonging survival, key goals of cancer care. Other studies have indicated that conversations during clinical interactions that respected personhood provided spaces for clients to clarify queries related to cancer conditions (Fitch, Greenberg, et al., 1998; Williams-Brown et al., 2005). Women described how health professionals' responsive actions to their informational and emotional needs validated their experiences and demonstrated respect (Williams-Brown et al., 2005). Moreover, Fitch, Greenberg, et al. reported that health professionals' rushed and uncaring attitude left women feeling belittled and disrespected. In addition, these authors found that being treated as a person was an essential aspect of a physician-patient relationship, because it showed the health professionals' sensitivity and humanness, thereby creating a shared humanity and respect. Respect has been identified as the essential structure of a caring health care encounter, especially when health professionals showed genuine concern and respect of the patient as a person (Halldorsdottir & Hamrin, 1997). These findings confirmed South Asian immigrant women's feelings of respect when health professionals showed genuine concern and paid attention to their needs during the cancer-related treatments in the clinical setting.

Ross and Johansen (2002) identified that the health professional's attitude is a crucial aspect of creating respect within health professional–client relationships. These authors have indicated that expressions of esteem relate to respect, whereby the patient is acknowledged as a fellow being rather than as merely a cancer patient. Wright and colleagues (2004) found that patients felt respected when they were valued as a "whole

person," which was important, because it allowed them to be "seen as an individual" (p. 865). Other related research has suggested that viewing the person as a whole person would respect that person's individualistic characteristics as well as his or her societal contributions, which helps that person to relate to the world in which he or she functions (Browne, 1995, 1997; Kitson, 2002; Travado et al., 2005).

These findings corroborate our finding that a "person-centered" approach created respect for women journeying through cancer, thereby promoting their health and well-being, which extended to health care outcomes and the women's ability to function as normally as possible within their society and in their families. This was especially true when clients were dealing with life-threatening cancer conditions that affected their ability to provide their families with financial and emotional support (Richardson, 2004). Jakobsson, Horvath, and Ahlberg (2005) shared respect as a strategy for achieving acceptance at clients' first visit to the cancer clinic. Findings in this previous study identified three dimensions to respect, namely, being treated as an individual, being given time during the consultation, and being treated with empathy. Health professionals' ability to be compassionate and share in cancer clients' experiences of suffering was consistently seen as being respectful and supportive emotionally, physically, mentally, and spiritually.

### Health Care Relations and Other Population

Studies with the elderly population in health care settings have shared the importance of assuring dignified and respectful care for all age groups (Calnan, Woolhead, Dieppe, & Tadd, 2005; Chao & Roth, 2005; Clegg, 2003; McLeod & Schwartz, 2000; Flesner, 2003; Raftopoulos, 2005). Demonstrating respect was

associated with providing culturally sensitive health care and promoting staff understanding when working with older South Asian patients in a hospital setting (Clegg, 2003). Respecting a person meant acknowledging a person's right to hold views, to make choices, and to take action on their personal values and beliefs. In addition, Clegg reported that respect flowed from the recognition that all persons have unconditional worth and that "being treated with respect and dignity meant being treated like I was somebody", (p. 286). This capacity to respect patients helped to maintain their humanity, identity and sense of self-respect as individuals. Calnan, Woolhead, Dieppe, & Tadd (2005) also identified dignity and respect as salient components of providing health care for the elderly, especially in light of technology and modernization of health care. Clegg (2003) acknowledged the differences in the way people of different cultures demonstrated respect, however, she asserts that "the basic tenet of all care is the recognition of one's individual humanity", (p. 286). Raftopoulos (2005) found patient's respect as a human being was a specific dimension of nursing and medical care. Other dimensions for creating respectful relationships were health professionals' technical skills and effective communication styles. Provision of person-centered care was seen as an enhancing factor when trying to achieve respect for each person's unique life long patterns, preferences and individuality (Flesner, 2003). Flesner identified that respect allowed personal growth and a sense of contribution which helped to develop connections within health professional–client relationships.

McLeod and Schwartz-Aiken (2000) reported that respect was frequently reported as a positive component of health care provision by older women. These authors found that respect for individuals' social needs, personal preferences, thoughts and feelings

along with their individuality manifested respect when providing care. McLeod and colleague identified "older women are worthy of being treated with honesty and respect" (p.6) as a theme, which included health professionals' willingness to listen to their clients. Respect for individuality seemed to be a key component of health care provision when working with the elderly population. Chao and Roth (2005) identified a caring attitude and respect for individual differences as two of the key dimensions of quality care in health care settings. Clients expected health professionals to respect their individual life style preferences and experiences that they brought with them to the hospital setting. This allowed them to keep their social identity intact while being hospitalized. Chao and colleague found that open and direct communication was a key factor in bestowing respect, especially when health professionals interacted with clients and their family members.The complexities inherent in interpersonal communications within health professional–client relationships have been the target of much research with those journeying through cancer.

## Communication within Health Professional–Client Relationships in the Context of the Clinical Setting

Roberts (2004) found that clinicians' giving the patient room to speak while engaging with them during history taking encouraged the patient to provide sensitive information while respecting their individuality, because the illness experiences, ultimately, belonged to the patient. Venkatesan (2004) stressed that communication underpinned partnership; therefore, really listening to a client meant not only understanding his or her perspective and priorities but also trying to engage with the meaning invested in the experience of the illness, creating respect, which validated the

client's suffering. Evidence from patient satisfaction studies and from social and linguistic studies of interaction has shown a strong relationship between involvement in talk and avoidance of misunderstanding for the health care provider and the recipient (Roberts, 2004). There is a strong association between health professionals' listening, ease of communication, and friendship, which help to build positive outcomes of trust, connectedness, belonging, being accepted, and being valued as a human being within the health professional–client relationship. Descriptions of health professionals' ways of talking with the women when interacting with them manifested respect and created rapport.

However, it was seen that rapport also depended on the health professional's attitude, not only the communication skills or strategies used during the clinical interactions (Ross & Johansen, 2002). In this study, women identified attitude as the health professionals' mindset or way of being. This way of being marked respect at the beginning of the health care relationship, whereas the actions were the health professionals' ability to listen and engage with the women during clinical interactions. Zimmermann (2002) identified the importance of the initial contact and greeting with a smile from the nurse's perspective of communicating with clients in the clinical setting. This previous author reported that being open beyond the mental attitude, that is making eye contact, saying hello, physically keeping the heart and body area open by uncrossing the arms, and paying attention to the person in the relationship acknowledges the other. In addition, Zimmermann shared that creating a happy ending by saying good-bye leaves a lasting impression, making the final moments more pleasant. Jakobsson and colleagues (2005) reported that health professionals' capacity to engage with clients and their use of

understandable language during clinical interactions meant that they were able to treat patients as individuals. Being treated as an individual related to being valued as women having an identity regardless of the cancer condition.

Most non–English-speaking women thought that the provision of interpreters enriched their understanding of cancer and its related treatments (Bottorff, Johnson, et al., 1998; Singh, 2002; Vydelingum, 2000, 2005). However, the unavailability of most written reading material in South Asian languages compromised the women's more complete understanding of their illness. Perry and colleagues (2002) have reported that this compromise in women's understanding of their illness influenced the quality of relationships with health professionals in the clinical setting. This lack of understanding further compromised women's health outcomes and their ability to make difficult decisions that affected them and their family members, especially when coping with life threatening cancer conditions (Varcoe, Rodney, & McCormick, 2003).

Findings from other studies have recognized that in institutions that serve a large South Asian immigrant population, interpreters could function as cultural mediators and advocates for South Asian immigrant women, especially if they were part of the institution, making them familiar with existing health care policies and procedures (Singh, 2002; Vydelingum, 2005). Another study that examined communication in cancer identified that cultural cancer navigators created a healthier, more respectful environment for oncology nurses as well as clients because of the decreased emotional stress and exhaustion and improved health professional–client relationships (Travado et al., 2005).

Research on health professionals' burnout symptoms in cancer care showed that frustrated health care relationships due to poor communication skills and language

barriers led to high emotional stress and detachment in dealing with patients and professionals' poor satisfaction with their work (Hack, Degner, & Parker, 2005; Harris & Templeton, 2001; Travado et al., 2005). Fitch et al. (1998) indicated that oncology nurses faced diverse challenges in the clinical setting while providing care and administering complex cancer-related treatments, and these challenges were heightened when the nurses were working with immigrants who might be non-English speaking. Tailoring communication style to fit with the patient, the type of cancer, and its related treatments was seen as creating respectful and satisfying relationships for both the health professional and the client (Buller & Buller, 1987). Kirkham (2003) has reported the need to challenge existing health care policies related to interpretive services and language-specific materials for diverse populations.

Other related studies with cancer patients have found that genuine open and sensitive communication reflected respect for the person who was suffering while conveying compassion (Arman, Rehnsfeldt, Lindholm, & Hamrin, 2002; Richardson, 2004). These researchers also found that patients valued and trusted physicians who were open and frank in their communication skills when addressing difficult cancer-related issues within health professional–client relationships. Similar findings emphasized openness in communication and genuine concern at the beginning of an encounter as part of building a caring professional health care relationship (Halldorsdottir & Hamrin, 1997). Some other elements of communication, such as greeting an individual and acknowledging the other, have been identified as having the ability to bestow respect, allowing clients to feel less like patients and more like whole persons whose psychosocial, physical, and emotional needs have been met (Thorne et al., 2005). Other

researchers have reported that greeting the patient, looking him or her in the eye, remembering his or her name, and shaking his or her hand were deemed essential aspects of being respected within the health professional–client relationship (Jakobsson et al., 2005). Greeting was considered a common courtesy owed to another, an inherently human reciprocal quality that recognized the other person's existence by paying attention to him or her, especially as greeting was considered a social relational aspect of a human-to-human relationship (Bergum, 1999).

Communication in health care settings has always been identified as complex because of contextual factors, such as social, individual, and institutional factors within the clinical setting. Therefore, we cannot state that patients' and health professionals' attributes, such as health care needs, skills, values, beliefs, and personal feelings, alone will influence how respect is conveyed and interpreted within health professional–client relationships (Butler, Degner, Baile, & Landry, 2005; Parker, Davison, Tishelman, & Brundage, 2005). Because beliefs and attitudes are complex concepts based on social, emotional, and behavioural factors, addressing a change in health professionals' attitude will reflect a change in communication style (Feldman-Stewart, Brundage, & Tishelman, 2005). Jenkins and Fallowfield (2002) found that physicians' attitudes toward clients and beliefs about psychosocial issues affected how they communicated with patients diagnosed with cancer. Findings in other studies with cancer communication showed that physicians working with cancer patients showed more positive attitudes toward psychosocial issues after attending intensive communication training programs (Fallowfield, Lipkin, & Hall, 1998). Fallowfield, Saul, and Gilligan (2001) reported that senior oncology nurses who had previously identified having difficulties in their

communication with patients appeared to gain confidence in their communication skills after adopting different teaching practices. Multiple studies have shown that a lack of quality communication skills in cancer care was the primary cause of burnout among health professionals because of the psychosocial and physical demands of providing care for cancer patients and their families (Buller & Buller, 1987; Hack, Degner, & Parker, 2005; Harris, Templeton, 2001; Parker, Davison, Tishelman, & Brundage, 2005; Feldman-Stewart, Brundage, & Tishelman, 2005; Thorne, Bultz, & Baile, 2005).

The other aspect of communication in cancer that has been studied is how much information cancer clients want during their cancer journeys. In our study, some women confessed they wanted as much information as possible, because it made them feel as if they had control over their disease, whereas others needed only enough information about the symptoms and side effects of the cancer related treatments. Similar findings from other studies have shown that patients differed regarding the information they wanted and needed concerning their cancer care (Brown, Carrol, Boon, & Marmoreo, 2002; Parker, Davison, Tishelman, & Brundage, 2005; Wright et al., 2004). It is often difficult for health professionals to estimate accurately or provide the amount and type of information patients want. The health professionals' inability to gauge how much information clients want might be perceived as respectful or not, depending on the women's personal experiences. Health care is best mediated through relationships, with the original contact and establishment of the health care relationship through exchange between the health professional and the client in the clinical setting. The ways in which health care is provided through communication creates respect within health professional–client

relationships, which, in turn, shapes the illness experiences of patients and families, influencing healing and possibly determining health outcomes (Wright et al., 2006).

### Fostering Respect within Health Professional–Client Relationships

The quality of health care relationships has been found to be an important determinant of health outcomes for patients and their family members, as well as creating positive practice environments for health professionals (Varcoe, Rodney, et al., 2003). More specifically, respect within health professional–client relationships was found to foster patients' well-being when patients felt acknowledged, accepted, and valued as people first and patients second (Arora, 2003; Browne, 1995, 1997; Fitch et al., 1998; Wright et al., 2004). Other similar findings have confirmed that the quality of health care relationships is a determinant of health outcomes for patients, the experiences of the family members, and the quality of work life of health care providers (Arman et al., 2002; Richardson, 2004; Wright et al., 2004). A number of studies addressing influence and quality of health care relationships on psychosocial adjustments for patients (Kayser, Sormanti, & Strainchamps, 1997; Thorne & Robinson,1988) and communication in cancer care (Harris & Templeton, 2001; Richardson, 2004; Thorne et al., 2005) have found that health professionals' attitudes when providing information and listening to patients' needs regarding their symptom management and side effects, and giving patients choices and options in relation to treatments created feelings of connectedness and respect by taking away the powerlessness that patients felt because of their cancer conditions.

Health care relationships between patients and health care providers are considered an integral component of health care delivery (Fox, 2003). In addition,

characteristics of respect, such as being attentive, accepting, and acknowledging the client enhanced the quality of health professional–client relationships, which, in turn, created a healing relationship when women felt they were given permission to hope and have faith when sharing their suffering with the nurse while receiving cancer-related treatments or with the physician when he or she provided information (Jakobsson et al., 2005; Thorne, Hislop, Kuo, & Armstrong, 2006).

Milton (2003) and Stanley (2002) stated that attending to a person, being truly present for him or her, being in the moment, and listening attentively are characteristics of respect in the nursing profession. These authors have found that health professionals' ability to listen attentively and to be present benefited the patient and their families. These characteristics created respect for the person and generating healing and safe health professional–client relationships, thereby increasing patient well-being along with positive health outcomes. Health professionals who partnered with the patient in an engaged manner and adopted a person-centred approach were seen as creating individuality for the patient in the health care setting (Fox, 2003; Frankel, Sung, & Hsu, 2005). Harris and Templeton (2001) reported that creating respect within health professional–client relationships and demonstrating an interest in the patient as a person who is aware of her situation and place in normal life, being human, and demonstrating genuine compassion helped health providers to avoid patronizing attitudes as the "experts."

Other studies that have examined physician–patient communication found that some physicians engaged in partnership building and supportive talk, which enhanced respect and supported a person-centered approach, thereby valuing and acknowledging

the patient's identity (Epstein, 2000; Street et al., 2005). Niven and Scott (2003) stressed that when the nurse attended fully to the client, it led to a more highly valued, patient-led approach compared to the regular patient assessment models apparent in the nursing profession. Frankel, Sung, and Hsu (2005) observed that optimal healing environments were created when mutual respect was present within heath professional–client relationships. Miller and Crabtree (2005) in an examination of optimal healing relationships found that one of the most important guiding principles was to "acknowledge everyone's personhood, so each emerges as a co-creative participant within the [relational] landscape" (p. 46). In addition, these authors suggested that respect, compassion, generosity, and humility are some of the factors that add to the quality of a healing relationship, thereby enhancing both participants in the relationship without negating the other in a clinical practice setting.

Varcoe, Rodney, et al. (2003) stressed that the sociopolitical context of practice and the individual's actions each influence the other. The complexity of providing care for culturally diverse clients can be addressed by creating safe environments in which frank but respectful discussions within health professional–client relationships can take place (Browne, 2003; Kirkham, 2003; Spitzer et al., 2003). Exchanging information on difficulties and enhancing strategies on communication skills will benefit not only nursing but families with cancer and other colleagues (Kitson, 2002). Critical self-awareness of the nurse's own culture and recognition of his or her biases can be learned and fostered to counter stereotyping (Kirkham, 2003; Reimer-Kirkham, 2000).

Providing culturally appropriate care prompts us to question our own assumptions about South Asian immigrant women, to locate women's health concerns within a

structural context, and to connect the dynamics of individual encounters to broader social, political, and economic issues (Browne & Fiske, 2001; D. E. Smith, 1987). Hunter, Logan, and Barton (2006) stressed the importance of respectful communication with a focus on bridging the cultural gap between the health care professional and the client, thereby fostering respect. These authors highlighted the importance of valuing the client's heritage and identity by respecting his or her personal experiences and the standpoint perspective that he or she brings to the health professional–client relationship.

Lysaught (2004) has provided a philosophical insight into how respect has functioned in the health care field. He extends the conundrums of providing respect within health professional–client relationships, especially in light of the cultural, societal, and individual differences among clientele in the current health care system. The common sense meaning of respect would be to honor and to value the other's uniqueness and to make space for them within the relationship. Lysaught (2004) further argued that health professionals capacity to treat a patient as a person stems from the principle of respect for persons. Hill (2000) shared that respect did not always have material gains and benefits, but something to which we should presume "every human being has a claim, namely, full recognition as a person" (p. 63), with the same worth and value that any other co-member within the community deserves. Clegg (2003) shared how the concept of respect for the individual was influenced in global terms by the political, social, economic, and religious interpretations. She further argued how the patient's individual humanity appears to cease when the patient enters the clinical setting. In light of these arguments and the discussion presented in this chapter, I ask, how can I as a health professional help to value an individual's worth and their social identity by

bestowing respect for those who are in relation with me in the institutionalized health care setting.

## Limitations and Strengths of the Study

Focused ethnography proved to be an effective means of studying the phenomena under investigation in this study. This qualitative research method facilitated a contextual understanding of the identified problem by allowing the data to be interpreted through a cultural lens (Hammersley & Atkinson, 1993; Spradley, 1979) and a critical approach using the feminist standpoint perspective (D. E. Smith, 1987). A central argument here for a focused ethnographic approach with the feminist critical perspective lens is that women's everyday experiences, as well their health care experiences, cannot be attributed solely to their "cultural differences" but must also be understood within the context of the larger social organization of health care structures (Morse & Field, 1995; D. G. Smith, 1994).

Although the focus of the study was on one cancer care agency, two separate clinical sites were used, which increased the number of participants and diversity among the population under study. The choice to conduct the study from only the clients' perspective was instrumental in providing a thorough and detailed account of South Asian immigrant women's stories of respect within health professional–client relationships in the clinical setting. This decision was also made because of the time and financial restraints involved in conducting dissertation research. The study was limited to South Asian immigrant women but did include immigrant women from the various subgroups within the South Asian immigrant women group. This representation of the four major subgroups (Hindi, Urdu, Punjabi, and Tamil speaking) of immigrant women

that make up the South Asian immigrant women population in the surrounding area provided diversity within the sample.

To some extent, the relatively small number of interviews conducted for this study might be a limiting factor. However, the diversity of the subgroups helped to increase the representation of the population under study. This study also gained strength from the diversity of participants' types of cancer experiences, which included breast, colon, tongue, and brain cancer. In addition, some participants were interviewed twice, which gave me access to changes in their perceptions of respect; however, these second interviews, in fact, helped to confirm the findings, especially as participants were chosen strategically to validate data.

Participant observation added to data and analysis by my gaining the insider's perspective, which provided a more complete and detailed picture of the contextual data of the settings. Observations made during participant observation enabled me to sift through the participants' experiences and field notes to identify and examine differences and similarities among the participants' experiences. Overall, the choice of the methods used to collect data, such as document retrieval and its analysis, the observations, and discussions with health professionals during the participant observation, helped to confirm the findings of respect within the participants' interviews. Nevertheless, I understand that the diversity of South Asian immigrant women's experiences and perceptions of respect might not be captured fully in the study. Although I acknowledge that this is by no means an exhaustive study, however, the findings provide valuable insight into South Asian immigrant women's experiences of respect within health professional–client relationships in an outpatient follow-up clinical setting.

I acknowledge that a multiplicity of influences such as literacy, socio-economic status, educational level, or social class, as distinct from culture, could be influential for perceptions of respect. A further analysis of these factors would shed light on their influence, as distinct from the influence of culture alone, and help to avoid the risk of attributing to culture what may be related to other factors. Although the emphasis in analysis in this study is on South Asian immigrant women's experience of respect within the structural context of the two clinical sites, it is acknowledged that the study has not addressed the broader social issues that a feminist analysis would often include such as gender, social class, multiculturism or consumerism which the findings suggest may also be relevant.

# CHAPTER SIX

# SUMMARY AND RECOMMENDATIONS

In this chapter, I present a summary of the findings, and then discuss contributions to nursing knowledge, nursing practice, and recommendations for future research directions in light of these findings. Concluding comments for this study highlights some of the simple ways in which health professionals can make a difference for clients during their clinical visits.

## Summary

The purpose of this focused ethnography was to examine South Asian immigrant women's experiences and perceptions of respect within health professional–client relationships. The women who participated in this study differed in age, education, fluency in English, types of cancer, and the number of years they had resided in Canada. Most women were going through chemotherapy and radiation treatments at the time of the study, whereas others had visited the outpatient clinic for routine follow-up posttreatment visits. Interpretation of the data provided insight into how these women perceived their experiences of respect in light of their heritage and personal experiences of immigration, transition, and previous health care experiences. In this study, the patients' perspective on respect was "evidence," or an account of "their" personal experiences, which was used as the departure point for informing the findings (Kitson, 2002).

This account of South Asian immigrant women's experiences is critical for health professionals who provide cancer care to diverse communities, as it locates clients' health concerns within a structural context and connects the dynamics of individual encounters

to broader social, political, and economic issues rather than the simplistic cultural view, which includes the values and beliefs of a group of people. Facilitating factors, such as health professionals' positive way of being and their communication styles, including their way of talking when providing information, along with their ability to acknowledge South Asian immigrant women as human beings, were identified as being respectful. Inhibiting factors, such as health professionals' making assumptions and stereotyping South Asian immigrant women as a group rather than considering them as individuals with their own personal experiences, were also identified.

## Contributions to Nursing Knowledge and Practice

The findings of this study contribute to existing nursing knowledge and inform practice in relation to provision of culturally sensitive health care to diverse ethnic populations by highlighting the complex factors that were at play when predominantly English-speaking health professionals provided health care at an outpatient follow-up clinical setting. Understanding the ways in which people's responses to health and illness are shaped by culture can help health professionals to adapt their practices to be more responsive to specific groups. However, culture is only one dimension of people's experiences (Anderson & Reimer-Kirkham, 1998). The problem with relying solely on enhancing cultural sensitivity to improve health care is that it wrongly assumes that one can know another culture, which is concrete, static, and applicable to all members of the group. These assumptions about culture perpetuate stereotypes of particular ethnocultural groups as outsiders and are problematic (Culley, 2001). An alternative approach is to recognize culture as inextricably tied to societal and institutional inequalities. Culture represents more than the beliefs, practices, and values of particular groups; it is also

located within a constantly shifting "network of meanings enmeshed within historical, social, economic and political processes" (Anderson & Reimer-Kirkham, 1998, p. 243).

I observed that a language barrier created difficulties when English-speaking health professionals' related important information about cancer and its related treatments with the help of interpreters. However, health professionals were unable to present non–English-speaking women with language-specific written educational material to fill in the information gaps, which would have enhanced the South Asian immigrant women's understanding of the cancer condition and its related treatments, along with providing them with the pertinent information that they needed to make their health care decisions.

Although providing culturally sensitive health care and use of interpreters are pivotal aspects of institutional health policies and guidelines, there are other humane ways of providing respect for the individual within the health professional–client relationship. Recognising the individual for his or her personal life experiences as someone who has mastered his or her own language along with some understanding of English can foster respect within health professional–client relationships. This strategy of recognizing the individual with his or her own standpoint and acknowledging his or her social identity bestows respect for the individual's location and life experiences, which he or she brings to the health professional–client relationship. This allows individuals to be seen for who "they are" as human beings, not as stereotypes of a particular ethnic group. In addition, this strategy helps to prevent health professionals from making assumptions and stereotyping people as part of the "other" ethnic group. The health professional shares humanity with the "other" people and creates respect by acknowledging the others' identity and personal life experiences, which will inform how they journey

through this cancer condition (Johnson, et al, 2004). This preliminary study about South Asian immigrant women's perceptions and experiences of respect within health professional–client relationships in a cancer agency clinical setting has contributed to the existing nursing knowledge and has generated questions to explore for future research. While this study with South Asian immigrant women was conducted within the nursing discipline in a social clinical setting, the findings may have a relevance to other health professionals who work with South Asian immigrant women in other clinical settings.

## Recommendations for Future Research Directions

The findings of this research add to the body of nursing knowledge by furthering understanding of multiple factors influencing South Asian immigrant women's experiences of respect within health professional–client relationships at both the micro level of interactions between clients and health professionals and the meso/macro levels of health care organizations. Based on the preliminary findings of respect from this study, questions were generated as outcomes of this study, and the following questions have been formulated as suggestions to provide direction to nurse-researchers, nurse-educators, and practice leaders as they consider expanding their foci in the area of immigrant population health. These questions and suggestions are deliberately contained within a few brief points to make them as accessible as possible.

1. How can respect be fostered within the daily routines of health care provision for the immigrant population as they enter the health professional–client relationship in a newly adopted country?

2. How significant and applicable is the concept of respect to the specific South Asian immigrant population group under study, to the other populations at the clinical health care setting, and to nursing in general?
3. How can respect be bestowed to its optimum through communication and language within health professional–client relationships?
4. How do we co-create optimal respect within health professional–client relationships, such that a healing landscape is created?
5. Maybe our most challenging question on the quest for optimal respect is how to accomplish respectful health care relations within the technology based and consumer-dominant world.
6. An exploration of respect with various populations in health care settings other than cancer settings will help to shed light on what clients expect when entering our health system.
7. Examine the theoretical and practice-oriented guidelines embedded within the provision of culturally sensitive health care that inhibit or enhance a person-centred approach within institutional settings.
8. Examine what impact broader social issues such as gender, class, socio-economic status, multiculturism, or consumerism have on how immigrant women experience respect within health professional–client relationships.
9. Critical analysis of the immigration/transition, and resettlement issues could facilitate an understanding of the experiences of the South Asian immigrant population as they adapt to the new country along with having to deal with a cancer condition. These can be accomplished through case studies or community-

based scenarios in nursing education and a thorough reexamination of South Asian immigrant women's experiences through a critical lens when conducting research.

## Concluding Comments

The findings in this study illuminated the various social, economic, cultural, individual, and institutional factors that coexist within the health professional–client relationship in a clinical setting in the mainstream health system in Canada. The strategies and recommendations discussed can help to inform nursing practice by providing insight into the way in which interactions with diverse ethnic populations can be handled to make a difference between respectful or non-respectful health professional–client relationships. As nurses and health professionals, we must make space for analysis of social, political, institutional, and experiential contextual factors, and how these have variously positioned us, shaped people's health, and structured our relations with one another; only then can we work to transform these health professional–client relationships (Browne, 2003).

Turning the critical gaze inward might be disconcerting to those of us who see ourselves as being critiqued and challenged; this is inevitable as dominant discourses and practices are scrutinized. However, we must interrogate our taken-for-granted assumptions about the "other," for it is only then that we as health professionals (human beings) can respect and acknowledge the other (human being), who is an individual with his or her own identity and personal experiences, regardless of ethnicity, colour, language, age, or gender.

**References**

Aamodt, A. M. (1991). Ethnography and epistemology: Generating nursing knowledge. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 40-53). Newbury Park, CA: Sage.

Acton, G. J., Irvin, B. L., Jensen, B. A., Hopkins, A., & Miller, E. W. (1997). Explicating middle-range theory through methodological diversity. *Advances in Nursing Science, 19*(3), 78-85.

Agar, M. G. (1986). *Speaking of ethnography: Qualitative research methods*. Beverley Hills, CA: Sage.

Ahmad, W. I. U. (1993). *"Race" and health in contemporary Britain*. Buckingham, UK: Open University Press.

Allen, D., & Cloyes, K. (2005). The language of "experience" in nursing research. *Nursing Outlook, 12*(2), 98-105.

Anderson, J. M. (1987). Migration and health: Perspectives on immigrant women. *Sociology of Health & Illness, 9*(4), 410-438.

Anderson, J. M. (1998). Speaking of illness: Issues of first generation Canadian women—Implications for patient education and counselling. *Patient Education and Counselling, 33*, 97-207.

Anderson, J. M., Blue, C., Holbrook, A., & Ng, M. (1998). On chronic illness: Immigrant women in Canada's work force—A feminist perspective. *Canadian Journal of Nursing Research, 25*(2), 7-22.

Anderson, J. M., Dyck, I., & Lynam, J. (1997). Health care professionals and women speaking: Constraints in everyday life and the management of chronic illness. *Health, 1*(1), 57-80.

Anderson, J. M., & Reimer Kirkham, S. (1998). Constructing nation: The gendering and racializing of the Canadian health care system. In V. Strong-Boag, S. Grace, A. Eissenberg, & J. Anderson (Eds.), *Painting the maple: Essays on race, gender, and the construction of Canada* (pp. 242-261). Vancouver, BC: UBC Press.

Appadurai, A. (1996). *Modernity at large: cultural dimensions of globalization*. Minneapolis: University of Minnesota Press.

Arman, M., Rehnsfeldt, A., Lindholm, L., & Hamrin, E. (2002). The face of suffering among women with breast cancer—Being in a field of forces. *Cancer Nursing, 25*(2), 96-104.

Arora, N. K. (2003). Interacting with cancer patients: The significance of physicians' communication behavior. *Social Science & Medicine*, *57*, 791-806.

Asselin, M. (2003). Insider research: Issues to consider when doing qualitative research in your own setting. *Journal for Nurses in Staff Development*, *19*(2), 99-104.

Atkinson, P., & Hammersley, M. (1994). Ethnography and participant observation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 248-261). Newbury Park, California: Sage.

Baider, L., & Bengel, J. (2001). Cancer and the spouse: Gender-related differences in dealing with health care and illness. *Critical Reviews in Oncology/Haematology*, *40*, 115-123.

Bakke, A., & King, D. (2000). A fundamental aspect of supportive care delivery: The nurse's opportunity to shape the caring encounter. *Journal of Paediatrics Oncology Nursing*, *17*(3), 182-187.

Beachamp, T. L., & Childress, J. F. (1994). *Principles of biomedical ethics* (4th ed.). New York: Oxford University Press.

Benjamin, M., & Curtis, J. (1992). *Ethics in nursing* (3rd ed.). New York: Oxford University Press.

Benner, P. (2002). Creating compassionate institutions that foster agency and respect. *American Journal of Critical Care*, *11*(2), 164-166.

Bergum, V. (1999). Ethics as question. In T. Kohn & R Mckenzie (Eds.), *Extending the boundaries of care: Medical ethics and caring practices* (pp. 167-180). New York: Oxford University Press.

Bergum, V., & Dossettor, J. (2003). Creating environment. In V. Bergum & J. Dossettor, *Relational ethics: The full meaning of mutual respect* (pp. 49-75). Haggarstown, MD: University Publishing Group.

Berman, B. A., Bastani, R., Nissenbaum, H., Henneman, B., & Crane, D. (1994). Cervical cancer screening among a low-income multiethnic population of women. *Journal of Women's Health*, *3*, 114-118.

Bhachu, P. (1996). Multiple landscapes of transnational Asian women in Diaspora. In V. Amit-Talai & C. Knowles (Eds.), *Re-situating identities: The politics of race, ethnicity, culture* (pp. 2383-303). Peterborough, ON: Broadview.

Bottorff, J. L., Balneaves, L. G., Sent, L., Grewal, S., & Browne, A. (2001). Cervical cancer screening in ethnocultural groups: Case studies in women-centered care. *Women & Health*, *11*, 322-337.

Bottorff, J. L., Johnson, J. L., Bhagat, R., Grewal, S., Balneaves, L. G., Clarke, H., et al. (1998). Beliefs related to breast health practices: The perception of South Asian women living in Canada. *Social Sciences & Medicine*, *47*, 2075-2098.

British Columbia Cancer Agency. (2002). *British Columbia Cancer Agency annual report: Trends in cancer incidence and mortality, 1974-1998*. Vancouver, BC: Andy Coldmann.

British Columbia Cancer Agency. (2005). *British Columbia Cancer Agency strategic plan*. Vancouver, BC.

Brodkey, L. (1987). Writing critical ethnographic narratives. *Anthropology & Education Quarterly*, *18*, 67-76.

Brown, J. B., Carroll, J., Boon, H., & Marmoreo, J. (2002). Women's decision-making about their health care: Views over the life cycle. *Patient Education and Counseling*, *48*, 225-231.

Browne, A. J. (1993). A conceptual clarification of respect. *Journal of Advanced Nursing*, *18*(2), 211-217.

Browne, A. J. (1995). The meaning of respect: A First Nation's perspective. *Canadian Journal of Nursing Research*, *27*(4), 95-109.

Browne, A. J. (1997). A concept analysis of respect: Applying the hybrid model in cross-cultural settings. *Western Journal of Nursing Research*, *19*, 762-780.

Browne, A. J. (2001). The influence of liberal political ideology on nursing science. *Nursing Inquiry*, *8*(2), 118-129.

Browne, A. J. (2003). *First Nations Women and health care services: The socio-political context of encounters with nurses*. Unpublished doctoral dissertation, University of British Columbia, Vancouver, BC, Canada.

Browne, A. J., & Fiske, J. (2001). First Nations women's encounters with mainstream health care services. *Western Journal of Nursing Research*, *23*,126-147.

Buller, M. K., & Buller, D. B. (1987). Physicians' communication style and patient satisfaction. *Journal of Health and Social Behavior*, *28*(4), 375-388.

Butler, L., Degner, L., & Baile, W. (2005). Developing communication competency in the Context of cancer: A critical interpretive analysis of provider training programs. *Psycho-Oncology*, *14*, 861-872.

Calnan, M., Woolhead, G., Dieppe, P., & Tadd, W. (2005). Views on dignity in providing health care for older people. *Nursing Times, 101*(33), 38-41.

Canadian Cancer Society. (2004). *Canadian cancer statistics annual report*. Vancouver, BC: Andy Coldmann.

Canadian Nurses Association. (2002). *Code of ethics for registered nurses*. Ottawa, ON: Author.

Carper, B. (1979). The ethics of caring. *Advances in Nursing Science, 1*(3), 11-19.

Carspecken, P. H. (1996). *Critical ethnography in education research: A theoretical and practical guide.* New York: Routledge.

Chao, S. & Roth, P. (2005). Dimensions of quality in long-term care facilities in Taiwan. *Journal of Advanced Nursing, 52*(6), 609-619.

Charmaz, K. (2004). Premises, principles, and practices in qualitative research: Revisiting the foundations. *Qualitative Health Research, 14*(7), 976-993.

Choudhry, U. K. (2001). Uprooting and resettlement of South Asian immigrant women. *Western Journal of Nursing Research, 23*(4), 376-393.

Choudhry, U. K., Jandu, S., Mahal, J., Singh, R., Sohi-Pabla, H., & Mutta, B. (2002). Health promotion and participatory action research with South Asian women. *Journal of Nursing Scholarship, 34*(1), 75-81.

Choudhry, U. K., Srivastava, R., & Fitch, M. I. (1998). Breast cancer detection practices of South Asian women: Knowledge, attitudes, and beliefs. *Oncology Nursing Forum, 25*, 1693-1700.

Clegg, A. (2003). Older South Asian patient and carer perceptions of culturally sensitive Care in a community hospital setting. *Journal of Clinical Nursing, 12,* 283-290.

Clifford, J. (1986). Introduction: Partial truths. In J. Clifford & G. E. Marcus (Eds.), *Writing culture: The poetics and politics of ethnography* (pp. 1-26). Berkeley: University of California Press.

Costello, R. B. (Ed.). (1996). *Random House Webster's college dictionary* (4th ed.). New York: Random House.

Cowin, G. (2002). Multiculturism: Simply a matter of respect. *Australian Nursing Journal, 10*(1), 40.

Cresswell, J. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks: CA: Sage.

Culley, L. (2001). Nursing, culture and competence. In *Ethnicity and nursing practice,* eds L. Culley and S. Dyson, 109-128. Basingstoke: Palgrave.

Cushing, P., & Lewis, T. (2002). Negotiating mutuality and agency in care-giving relationships with women with intellectual disabilities. *Hypatia*, *17*(3), 173-193.

Das Gupta, T. (1994). Political economy of gender, race and class: Looking at South Asian immigrant women in Canada. *Canadian Ethnic Studies*, *26*(1), 59-73.

Das Gupta, T. (1994). Multiculturalism policy: a terrain of struggle for immigrant women. *Canadian Woman Studies, 14*(2), 72-77.

Davis, A. J., & Aroskar, M. A. (1991). *Ethical dilemmas and nursing practice* (3rd ed.). Norwalk, CT: Appleton-Century-Crofts.

Dedier, J., Penson, R., Williams, W., & Lynch, T. (1999). Race, ethnicity, and the patient-caregiver relationship. *The Oncologist*, *4*, 325-331.

Deeny, K., & McGuigan, M. (1999). The value of the nurse-patient relationship in the care of cancer patients. *Nursing Standard*, *13*(33), 45-70.

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2000). *Handbook of qualitative research* (2nd ed.).Newbury Park, California: Sage

DeVault, M. (1999). Talking and listening from women's standpoint: Feminist strategies for interviewing and analysis. In M. L. DeVault, *Liberating method: Feminism and social research* (pp. 43-59). New York: Temple University Press.

Dillon, R. (1992). Respect and care: Toward a moral integration. *Canadian Journal of Philosophy*, *22*, 105-132.

Dimond, B. (1999). Confidentiality: Nurses duty to respect patient confidentiality. *British Journal of Nursing*, *8*(9), 560-562.

Doane, G. H. (2003). Through pragmatic eyes: Philosophy and the re-sourcing of family nursing. *Nursing Philosophy*, *4*, 25-32.

Downie, R. S., & Telfer, E. (1970). *Respect for persons.* London: Allen and Unwin.

Drew, N. (1986). Exclusion and confirmation: A phenomenology of patients' experiences with caregivers. *Image: Journal of Nursing Scholarship*, *18*(2), 39-43.

Duarte Enes, S. P. (2003). An exploration of dignity in palliative care. *Palliative Medicine*, *17*, 263-269.

Dyck, I., Lynam, J. M., & Anderson, J. M. (1995). Women talking: Creating knowledge through difference in cross-cultural research. *Women's Studies International Forum, 18* (5/6), 611-626.

Ellen, R. F., (1984). *Ethnographic research: A guide to general conduct.* Orlando, FL: Academic Press.

Elliot, S. J., & Gillie, J. (1998). Moving experiences: A qualitative analysis of health and migration. *Health and Place, 4*(4), 327-339.

Emerson, R., Fretz, R. I., & Shaw, L. A. (1995). *Writing ethnographic field notes.* Chicago: University of Chicago Press.

Epstein, R. M. (2000). The Science of patient–centered care. *The Journal of Family Practice, 49,* (9), 805-807.

Erlen, J. A. (1998). Culture, ethics, and respect: The bottom line is understanding. *Orthopaedic Nursing, 17*(6), 79-82.

Fallowfield, L., Lipkin, M., & Hall, A. (1998). Teaching senior oncologists communication skills: Results from Phase 1 of a comprehensive longitudinal program in the UK. *Journal of Clinical Oncology, 12*, 1961-1968.

Fallowfield, L., Saul, J., & Gilligan, B. (2001). Teaching senior nurses how to teach communication skills in oncology. *Cancer Nursing, 24*(3), 185-191.

Feldman-Stewart, D., Brundage, M. D., & Tishelman, C. (2005). A conceptual framework for patient-professional communication: An application to the cancer context. *Psycho-Oncology, 14*, 801-809.

Fetterman, D. M. (1998). Ethnography. In L. Bickman & D. J. Rog (Eds.), *Handbook of applied social research methods* (pp. 473-503).

Fitch, M. I. (2000). Supportive care for cancer patients. *Hospital Quarterly*, 39-46.

Fitch, M. I., Greenberg, M. M. S., Cava, M., Spaner, M. S., Donna, M. D., & Taylor, K. (1998). Exploring the barriers to cervical screening in an urban Canadian setting. *Cancer Nursing, 21*(6), 441-449.

Fitch, M. I., Ross, R. E., & Franssen, E. (2001). Perspectives on living with ovarian Cancer: Older women's views. *Oncology Nursing Forum, 28*(9), 1433-1442.

Flesner, M. K. (2003). *Person centered care: A model for nursing homes.* Unpublished doctoral dissertation, University of Missouri – Columbia.

Forchuk, C. (1995). Uniqueness within the nurse-client relationship. *Archives of Psychiatric Nursing, 9*(1), 34-39.

Forchuk, C., & Reynolds, W. (2001). Clients' reflections on relationships with nurses: Comparisons from Canada and Scotland. *Journal of Psychiatric and Mental Health Nursing, 8*, 45-51.

Fox, S. A. (2003). Health effects of the patient-provider relationship: An interpretive study of the lived experience of women with chronic disease. Unpublished doctoral dissertation, University of California, San Francisco, California.

Frankel, R. M., Sung, S. H., & Hsu, J. T. (2005). Patients, doctors, and videotape: A prescription for creating optimal healing environments? *The Journal of Alternative and Complementary Medicine, 11*(S1) S31- S39.

Fredriksson, L., & Erickson, K. (2003). The ethics of the caring conversation. *Nursing Ethics, 10* (2),136-148.

Ganesh, K. (1993). Breaching the wall of difference: Fieldwork and a personal journey to Srivaikuntam, Tamilnadu. In D. Bell, P. Caplan, & W. Jahan Karim (Eds.), *Gendered fields* (pp. 128-142). London: Routledge.

Gans, H. J. (1997). Toward a reconciliation of "assimilation" and "pluralism": The interplay of acculturation and ethnic retention. *International Migration Review, 31*, 875-892.

Gans, H. J. (1999). Filling in some holes: Six areas of needed immigration research. *American Behavioural Scientist, 42*(9), 1302-1313.

Geertz, C. (1973). *The interpretation of cultures.* New York: Basic Books.

Gibbs, K. A. (2005). Teaching student nurses to be culturally safe: can it be done? *Journal of Transcultural Nursing, 16*(4), 356-360.

Gray, R. E., Goel, V., Fitch, M. I., Franssen, E., Chart, P., Greenberg, M., et al. (2000). Utilization of professional supportive care services by women with breast cancer. *Breast Cancer Research and Treatment, 64*, 253-258.

Grewal, S., Bottorff, J. L., & Balneaves, L. G. (2004). A Pap test screening clinic in South Asian community of Vancouver, British Columbia: Challenges to maintaining utilization. *Public Health Nursing, 21*(5), 412-418.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.

Gupta, A., Kumar, A., & Stewart, D. E. (2002). Cervical cancer screening among South Asian women in Canada: The role of education and acculturation. *Health Care For Women International*, *23*, 123-134.

Hack, T. F., Degner, L. F., & Dyck, D. G. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Social Sciences & Medicine*, *39*(2), 279-289.

Hack, T. F., Degner, L. F., Parker, P. A. (2005). The communication goals and needs of cancer patients: A review. *Psycho-Oncology*, *14*, 831-845.

Hall, S. (1994). *Cultural studies: Two paradigms*. Princeton, NJ: Princeton University Press.

Hall, J. M., & Stevens, J. E. (1991). Rigor in feminist research. *Advanced Nursing Science*, *13*(3), 16-29.

Halldorsdottir, S., & Hamrin, E. (1997). Caring and uncaring encounters within nursing and health care from the cancer patient's perspective. *Cancer Nursing*, *20*(2), 120-128.

Hammersley, M., & Atkinson, P. (1995). *Ethnography: Principles in practice*. London: Routledge.

Harding, S. (1991). What is feminist epistemology? In S. Harding, *Whose science/whose knowledge? Thinking from women's lives* (pp. xx-yy). Ithaca, NY: Cornell University Press.

Harding, S. (1995). The question of method. In A. Omery, C. E. Kasper & G. G. Page (Eds.), *In search of nursing science* (pp. 106-123). Thousand Oaks, CA: Sage.

Harding, S. (2003). Social mobility and self-reported limiting long-term illness among West Indian and South Asian migrants living in England and Wales. *Social Science & Medicine*, *56*(2), 355-361.

Harris, S. R., & Templeton, E. (2001). Who's listening? Experiences of women with breast cancer in communicating with physicians. *Breast Journal*, *7*(6), 444-449.

Hartrick, G. A. (2001). Beyond international communication: The significance of relationship in health promotion practice. In L. Young & V. Hayes (Eds.), *Transforming health promotion practice: Concepts, issues, and applications* (pp. 44-69). Philadelphia: F. A. Davis.

Hayes, L. (1995). Unequal access to midwifery care: a continuing problem? *Journal of Advanced Nursing, 21,* 702-707.

Henderson, V. (1978). The concept of nursing. *Journal of Advanced Nursing, 3*, 113-130.

Hill, T. (1982). Self-respect reconsidered. In O. H. Green (Ed.), *Respect for persons* (pp. xx-yy). New Orleans, LA: Tulane University Press.

Hill, T. E. (2000). *Respect, pluralism, and justice.* Oxford, UK: Oxford University Press.

Hilton, B.A., Grewal, S., Popatia, N., Bottorrf, J. L., Johnson, J. L., Clarke, H., et al. (2001). The desi ways: Traditional health practices of South Asian women in Canada. *Health Care for Women International*, *22*(6), 553-567.

Hislop, T. G., Inrig, K. M., Bajdik, C. D., Deshcamps, M., Tu, S. P., & Taylor, V. M. (2003). Health care services and Pap testing behavior for Chinese women in British Columbia. *Journal of Immigrant Health*, *5*(4), 143-152.

Holstein, J., & Gubrium, J. (1995). The active interview. In M. Miller, P. Manning, & J. Vaan Maanen (Eds.), *Qualitative research methods* (pp. xx-yy). Thousand Oaks, CA: Sage.

Howard, J. (1975). Humanization and dehumanization of health care. In J. Howard & A. Strauss (Eds.), *Humanizing health care* (pp. 2057-2102). City: Publisher.

Howell, D., Fitch, M. I., & Deane, K. A. (2003). Women's experiences with recurrent ovarian cancer. *Cancer Nursing*, *26*(1), 10-17.

Huberman, A. M., & Miles, M. B. (1998). Data management and analysis methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp. 179-210). Thousand Oaks, CA: Sage.

Hunter, L. M., Logan, J., Goulet, J., & Barton, S. (2006). Aboriginal healing: regaining balance and culture. *Journal of Transcultural Nursing, 17*(1), 13-22.

Jenkins, V., & Fallowhead, L. (2002). Can communication skills training alter physicians' beliefs and behavior in clinics? *Journal of Clinical Oncology*, *20*(3), 765-769.

Johnson, J. L., Bottorff, J. L., Browne, A. J., Grewal, S., Hilton, B. A., & Clarke, H. (2004). Othering and being othered in the context of health care services. *Health Communication, 16*(2), 253-271.

Johansson, P., Oleni, M., & Fridlund, B. (2002). Patient satisfaction with nursing care in Context of health care: A literature study. *Scandinavian Journal of Caring Sciences*, *16*, 337-344.

Kayser, K., Sormanti, M., & Strainchamps, E. (1997). Women coping with cancer: The Influence of relationship factors on psychological adjustment. *Psychology of Women Quarterly, 23*, 725-739.

Kelly, B. (1987). *Perception of professional ethics among senior baccalaureate nursing students.* Unpublished doctoral dissertation, Ohio State University, City.

Kelly, B. (1990). Respect and caring: Ethics and the essence of nursing. In M. M. Leininger (Ed.), *Ethical and moral dimensions of care* (pp. xx-yy). Detroit, MI: Wayne State University Press.

Kelly, B. (1991). The professional ethics of English nursing undergraduates. *Journal of Advanced Nursing, 16*(7), 872-876.

Kelly, B. (1992). Professional ethics as perceived by American nursing undergraduates. *Journal of Advanced Nursing, 17*(1), 10-15.

Kernohan, E. E. (1996). Evaluation of a pilot study for breast and cervical screening with Bradford's minority ethnic women: A community development approach. *British Journal of Cancer, 29* (Suppl.), S42-S46.

Kim, H. S. (1983). *The nature of theoretical thinking in nursing.* Norwalk, CT: Appleton & Lange.

Kirkham, S. (2003). The politics of belonging and intercultural health care. *Western Journal of Nursing Research, 25*(7), 762-770.

Kirkham, S. R., Pesut, B., Meyerhoff, H., & Sawatzky, R. (2004). Spiritual caregiving at the juncture of religion, culture, and state. *Canadian Journal of Nursing Research, 36*(4), 148-169.

Kitson, A. (2002). Recognizing relationships: Reflections on evidence-based practice. *Nursing Practice, 9* (3),179-186.

Kleinman, A., Das, V., & Lock, M. (1997). *Social suffering.* Berkeley: University of California Press.

Klutgen, J. (1995). *Autonomy and intervention.* New York: Oxford University Press.

Kusow, A. (2003). Beyond indigenous authenticity: Reflections on the insider/outsider debate in immigration research. *Symbolic Interaction, 26*(4), 591-600.

Landmark, B. T., & Wahl, A. (2002). Living with newly diagnosed breast cancer: A qualitative study of 10 women with newly diagnosed breast cancer. *Journal of Advanced Nursing, 40*(1), 112-121.

Lather, P. (1991). *Getting smart: Feminist research and pedagogy with/in the post-modern.* New York: Routledge.

Lawrence-Lightfoot, S. (2000). *Respect.* New York: Perseus.

Leininger, M. M. (1985). *Qualitative research methods in nursing.* Philadelphia: W. W. Saunders.

Lipson, J. G., & Meleis, A. I. (1985). Culturally appropriate care: The case of immigrants. *Topics in Clinical Nursing, 7*(3), 48-56.

Liu, J. E., Mok, E., & Wong, T. (2005). Perceptions of supportive communication in Chinese patients with cancer: experiences and expectations. *Journal of Advanced Nursing, 52*(3), 262-270.

Luoma, M., & Hakamies-Blomqvist, L. (2004). The meaning of quality of life in patients being treated for advanced breast cancer: A qualitative study. *Psycho-Oncology, 13*, 729-739.

Lynam, J. M., Henderson, A., Browne, A., Syme, V., Semeniuk, P., Blue, C., et al. (2003). Healthcare restructuring with a view to equity and efficiency: Reflections on unintended consequences. *Nursing Leadership, 16*(1), 112-140.

Lynam, J. M., & Young, R. A. (2000). Towards the creation of a culturally safe research environment. *Health, 4*(1), 5-23.

Lysaught, M. T. (2004). Respect: Or, how respect for persons became respect for autonomy. *Journal of Medicine and Philosophy, 29*(6), 665-680.

May, C. R., & Purkis, M. E. (1995). The configuration of nurse-patient relationships: A critical view. *Scholarly Inquiry for Nursing Practice: An International Journal, 9*, 283-294.

McDougall, M., Lasswell, H., & Chen, L. (1980). *Human rights and world public order: The basic policies of an international law of human dignity.* New Haven, CT: Yale University Press.

McGee, P. (1994). The concept of respect in nursing. *British Journal of Nursing, 3*(13), 681-684.

McLeod, E. J., & Schwartz-Aiken, F. E. (2000). Relationships of older women: Exploring the implications for health professionals. *Perspectives, 24*(4), 2-9.

McCormick, J., Kirkham, S. R., & Hayes, V. (1998). Abstracting women: essentialism in women's health research. *Heath Care for Women International, 19*, 495-504.

McMurchy, D., & Vujicic, M. (2001). The changing dynamics of the patient-provider relationship. *Hospital Quarterly, VOLUME*, 40-43.

Meleis, A. I. (1996). Culturally competent scholarship: Substance and rigor. *Advanced Nursing Science, 19*(2), 1-16.

Merton, R. K. (1973). The perspective of insiders and outsiders. In N. W. Storer (Ed.), *The sociology of science: Theoretical and empirical investigations* (pp. 99-136). Chicago: University of Chicago Press.

Miller, W. L., Crabtree, B. F. (2005). Healing landscapes: patients, relationships, and creating optimal healing places. *The Journal of Alternative and Complementary Medicine, 11*(S1), S41-S49.

Milne, A. (1986). *Human rights and human diversity: An essay in the philosophy of human.* New York: State University Press.

Milton, C. L. (1994). The American Nurses Association code of ethics: A reflection on the ethics of respect and human dignity with nurse as expert. *Nursing Science Quarterly, 16*(4), 301-304.

Milton, C. L. (2003). Stories: Implications for nursing ethics and respect for another. *Nursing Science Quarterly, 17*, 208-211.

Morris, N. M. (1997). Respect: Its meaning and measurement as an element of patient care. *Journal of Public Health Policy, 18*(2), 133-151.

Morse, J. M. (1992). *Qualitative health research.* Newbury Park, CA: Sage.

Morse, J. M., & Field, P.A. (1995). *Qualitative research methods for health professionals* (2nd ed.). Thousand Oaks, CA: Sage.

Morse, J. M., & Richards, L. (2002). *Readme first for a user's guide to qualitative methods.* Thousand Oaks, CA: Sage.

Moyle, W. (2003). Nurse-patient relationship: A dichotomy of expectations. *International Journal of Mental Health Nursing, 12*, 103-109.

Muecke, M. A. (1994). On the evaluation of ethnographies. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 187-209). Thousand Oaks, CA: Sage.

Mystakidou, K., Parpa, E., Tsilika, E., Katsouda, E., & Vlahos, L. (2004). Cancer information disclosure in different cultural contexts. *Support Care Cancer, 12*, 147-154.

Naish, J., Brown, J., & Denton, B. (1994). Intercultural consultations: Investigation of factors that deter non-English speaking women from attending their general practitioners for cervical screening. *British Medical Journal, 309*, 1162-1128.

Narayan, K. (1993). How native is a "native" anthropologist? *American Anthropologist, 95*, 671-686.

Neufeld, A., Harrison, M. J., Hughes, K. D., Spitzer, D., & Stewart, M. J. (2001). Participation of immigrant women caregivers in qualitative research. *Western Journal of Nursing Research, 23*(6), 575-592.

Niven, C. A., Scott, P. A. (2003). The need for accurate perception and informed judgement in determining the appropriate use of the nursing resource: hearing the patient's voice. *Nursing Philosophy, 4*, 201-210.

Oakley, A. (1981). Interviewing women: A contradiction in terms. In H. Roberts (Ed.), *Doing feminist research* (pp. 30-61). London: Routledge & Paul.

O' Baugh, J., Wilkes, L. M., Luke, S., & George, A. (2003). "Being positive": Perceptions of patients with cancer and their nurses. *Journal of Advanced Nursing, 44*(3), 262-270.

Oberle, K., & Tenove, S. (2000). Ethical issues in public health nursing. *Nursing Ethics, 7*, 425-438.

Parker, P. A., Davison, B. J., Tishelman, C., & Brundage, M. D. (2005). What do we know about facilitating patient communication in the cancer care setting? *Psycho-Oncology, 14*, 848-858.

Paterson, J. G., & Zderad, L. T. (1976). *Humanistic nursing.* New York: Wiley.

Perry, J., Lyman, M. J., & Anderson, J. M. (2004). Resiting vulnerability: The experiences of families who have kin in hospital–a feminist ethnography. *International Journal of Nursing Studies, 34,* 173-184.

Peters, R. S. (1961). Respect for persons and fraternity. In R. S. Peters (Ed.), *Ethics and education*, (pp. 133-137). Palo Alto, CA: Scott & Foresman.

Pham, C. T., & McPhee, S. J. (1992). Knowledge, attitudes and practices of breast and cervical cancer among Vietnamese women. *Journal of Cancer Education, 7*, 305-310.

Radley, A. (1993). *Worlds of illness: Biographical and cultural perspectives on health and disease.* London: Routledge.

Rajaram, S. S., & Rashidi, A (1999). Asian-Islamic women and breast cancer screening: A socio-cultural analysis. *Women & Health, 28*, 45-58.

Reimer-Kirkham, S. R. (1998). Nurses' description of caring for culturally diverse clients. *Clinical Nursing Research, 7*(2), 125-146.

Reimer Kirkham, S. (2000). *Making sense of difference: The social organization of intergroup relations in health care provision.* Unpublished doctoral dissertation, University of British Columbia, Vancouver, British Columbia, Canada.

Reimer Kirkham, S., Smye, V., Tang, S., Anderson, J., Browne, A., Coles, R., et al. (2002). Rethinking cultural safety. *Research in Nursing and Health, 25*, 222-232.

Reinharz, S. (1992). *Feminist methods in social research.* New York: Oxford University Press.

Richardson, A. (2004). Creating a culture of compassion: Developing supportive care for people with cancer. *European Journal of Oncology Nursing, 8*, 293-305.

Roberts, C. (2004). "Only connect": The centrality of doctor-patient relationships in primary care. *Family Practice, 21*(3), 232-233.

Robinson, J., & Elkan, R. (1996). *Health needs assessment: Theory and practice.* Edinburgh, UK: Churchill Livingstone.

Rogers, S. (1996). Facilitative affiliation: Nurse-client interactions that enhance healing. *Issues in Mental Health Nursing, 17*(3), 171-184.

Rokeach, M. (1979). *Understanding human values.* New York: Free Press.

Roper, J. M., & Shapiro, J. (2000). *Ethnography in nursing research.* Thousand Oaks, CA: Sage.

Ross. L, Johansen, C. (2002). Psychosocial home visits in cancer treatment: A qualitative study on the content of home visits. *Cancer Nursing, 25*(5), 350-357.

Rumbaut, R. (1999). Immigration research in the United States: Social origins and future orientations. *American Behavioural Scientist, 42*(9), 1285-1301.

Sandeloswki, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*, 27-37.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science,16*, 1-8.

Sandelowski, M. (1995). Focus on qualitative methods: Sample size in qualitative research. *Research in Nursing & Health, 18*, 179-183.

Schultz, D. S., & Carnevale, F. A. (1996) Engagement and suffering in responsible caregiving: On overcoming malfeasance in health care. *Theoretical Medicine, 17*, 189-207.

Seow, A., Wong, M. L., Smith, W. C. S., & Lee, H. P. (1995). Beliefs and attitudes as determinants of cervical cancer screening: A community-based study in Singapore. *Preventive Medicine, 24*, 134-141.

Sherwood, G. D. (2000). The power of nurse-client encounters: Interpreting spiritual themes. *Journal of Holistic Nursing, 18*(2), 159-175.

Singh, S. W. (2002). *An exploration of South Asian women's experiences following abnormal Pap smear results.* Unpublished master's thesis, University of British Columbia, Vancouver, British Columbia.

Smith, D. E. (1987).*The everyday world as problematic: A feminist sociology.* Boston: Northeastern University Press.

Smith, D. E. (1991). *Reflections on feminist scholarship.* Vancouver: University of British Columbia Press.

Smith, D. G. (1994). On being critical about language: The critical theory tradition and implications for language education. In *Pedagon: Meditations of pedagogy and culture* (pp. 137-150). Bragg Creek, AB: Makyo.

Smye, V., & Browne, A. (2003). "Cultural safety" and the analysis of health policy affecting aboriginal people. *Nurse Researcher, 9*(3), 43-56.

Spitzer, D. L. (2000). "They don't listen to your body": Minority women, nurses and childbirth under health reform. In D. Gustafson (Ed.), *Care and consequences: the impact of health care reform* (pp. 85-106). Halifax, NS: Fernwood.

Spitzer, D. L. (2004). In visible bodies: Minority women, nurses, time, and new economy of care. *Medical Anthropology Quarterly, 18*(4), 490-508.

Spitzer, D., Neufeld, A., Harrison, M., Hughes, K., & Stewart, M. (2003). Care giving in the transnational context: "My wings have been cut: Where can I fly?" *Gender and Society, 2*(10), 1-20.

Spradley, J. P. (1979). *The ethnographic interview.* Orlando, FL: Holt, Rinehart & Winston.

Stanley, K. J. (2002). The healing power of presence: Respite from the fear of abandonment. *Oncology Nursing Forum*, *29*(6), 935-940.

Statistics Canada. (2003). *Census of population-immigrant population by place of birth and period of immigration.* Retrieved April 3, 2004, from http://www.statscan.ca/english

Stephen, T. (1994). Exploring respect. *CAET Journal*, *13*(1), 7-13.

Stevens, S. B. (1993). *Community based programs for a multicultural society*. Winnipeg, Manitoba: Kromar Printing Ltd.

Street, R. L., Gordon, H. S., Ward, M. M., Krupat, E., & Kravitz, R. L. (2005). Patient participation in medical consultations, why some patients are more involved than others. *Medical Care, 43*(10), 960-969).

Tang, S. Y. S. (1999). Interpreter services in healthcare: Policy recommendations for health care services. *JONA*, *29*(6), 23-29.

Tarlier, D. S. (2004). Beyond caring: The moral and ethical bases of responsive nurse-patient relationships. *Nursing Philosophy*, *5*, 230-241.

Thayer-Bacon, B. J. (2000). *Transforming critical thinking, thinking constructively.* New York: Teachers College Press.

Thayer-Bacon, B. J. (2003). *Relational epistemologies.* New York: Peter Lang.

Thorne, S., Bultz, B. D., & Baile, W. F. (2005). Is there a cost to poor communication in cancer care?: A critical review of the literature. *Psycho-Oncology*, *14*, 875-884.

Thorne, S. E., Harris, S. R., Hislop, T. G., & Vestrup, J. A. (1999). The experience of waiting for diagnosis after an abnormal mammogram. *The Breast Journal, 5*(1), 42-51.

Thorne, S., Kuo, M., Armstrong, E., McPherson, G., Harris, S. R., & Hislop, G. T. (2005). "Being known": Patients perspectives of the dynamics of human connections in cancer care. *Psycho-Oncology*, *14*, 887-898.

Thorne, S. E., & Robinson, C. A. (1988). Health care relationships: The chronic illness Perspective. *Research in Nursing and Health, 11*, 293-300.

Tomaino-Brunner, C., Freda, M. C., & Runowicz, R. (1996). "I hope I don't have cancer": Colposcopy and minority women. *Oncology Nursing Forum*, *23*, 39-44.

Travado, L., Grassi, L., Gil, F., Ventura, C., & Martins, C. (2005). Physician-patient communication among Southern European cancer physicians: The influence of psychosocial orientation and burnout. *Psych-Oncology, 14*, 661-670.

Varcoe, C., & Rodney, P. (2002). Constrained agency: The social structure of nurse's work. In B. S. Bolaria & H. D. Dickinson (Eds.), *Health, illness, and health care in Canada* (pp. 102-128). City: Nelson Canada.

Varcoe, C., Rodney, P., & McCormick, J. (2003). Health care relationships in context: An analysis of three ethnographies. *Qualitative Health Research, 13*(7), 957-973.

Venkatesan, S. (2004). Children with developmental disabilities. A training guide for parents, teachers and caregivers. *Disability & Society, 19*(6), 677-680.

Vydelingum, V. (2000). South Asian patients' lived experience of acute in an English hospital: A phenomenological study. *Journal of Advanced Nursing, 32*(1), 100 107.

Vydelingum, V. (2005). Nurses' experiences of caring for South Asian minority ethnic patients in a general hospital in England. *Nursing Inquiry, 13*(1), 23-32.

Watson, C. W. (1999). *Being there: Fieldwork in anthropology*. London: Pluto.

Werner, O., & Schoepfle, G. M. (1987). *Systematic fieldwork: Foundations of ethnography and interviewing.* Newbury Park, CA: Sage.

Wheatley, M. J. (1994). *Leadership and the new science.* San Francisco: Berret-Koehler.

Williams-Brown, S., Meinersmann, K., Baldwin, D., & Phillips, J. M. (2005). Rural African American women's descriptions of mammogram quality. *Journal of Nursing Care Quality, 20*(3), 231-237.

Wolf, D. (1996). Situating feminist dilemmas in fieldwork. In D. Wolf (Ed.), *Feminist dilemmas in fieldwork* (pp. 1-41). Boulder, CO: Westview.

Wright, E. B., Holcombe, C., & Salmon. (2004). Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *British Medical Journal, 10*, 1136-1140.

Zimmerman, P. G. (2002). Improving employee communication in the clinical setting. *Journal of the American Association of Occupational Health Nurses, 50*(11), 515-519.

# Appendices

Appendix A: Request for access to the British Columbia Cancer Agency

Appendix B: Information Letter

Appendix C: Volunteer Recruitment Poster and A Brief Overview of the Study

Appendix D: Patient Informed Consent (English)

Appendix E: Participant Observation Field Notes Guide

Appendix F: Sample Interview Trigger Questions

Appendix G: Interview Field Notes Guide

Appendix H: Agencies' Mission and Strategy Plan, Policies, and Guidelines

Appendix I: List of Educational Material

Appendix A

Request for Access to the British Columbia Cancer Agency

June 6th 2005

British Columbia Cancer Agency
600 west 10th avenue
Vancouver, BC
V5Z 4E6

Dear Ms. Fiona Bees;

This letter follows my meeting with you in May 2005 regarding a letter of support and access for a research study as part of my PhD studies in nursing at the University of Alberta, Edmonton.

The purpose of this inquiry is to examine South Asian immigrant women's experiences and perceptions of respect within health professional-client relationships. South Asian women who come to a health care agency outpatient follow-up clinic for cancer related treatments will be participants in the study.

I plan to shadow health care professionals from different disciplines at both outpatient clinical sites over a period of two weeks before and after data collection in order to provide contextual data. This will be done with a verbal consent from health professionals and the patients they car for on that day.

I plan to recruit South Asian immigrant women from both Vancouver and Surrey outpatient clinic locations of the cancer agency. Recruitment will be done by asking the charge nurse to provide women with an information letter and recruitment advertisements on the BCCA bulletin boards.

I plan to begin data collection at the cancer agency sometime in August 2005 after receiving ethical approval from Health Research Ethics Board from the University of Alberta, Edmonton.

I would appreciate a letter of support granting access to the British Columbia Cancer Agency after ethical approval from the University of Alberta. This letter of support will form part of the Health Research Ethics Board application to the University of Alberta.

Thank you for your consideration.

Yours sincerely
Savitri Singh RN MSN PhD (pc), Faculty of Nursing
University of Alberta, Edmonton
ssingh@ualberta.ca

Appendix B

Information letter

**South Asian Women's Perceptions of Respect within Health Professional/Client Relationships While Journeying through Cancer**

Contact person: Savitri Singh RN MSN
PhD student, Faculty of Nursing
University of Alberta
Edmonton, Alberta
Vancouver number: 778-881-9130
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Supervisor: Anne Neufeld RN PhD
Professor, Faculty of Nursing
University of Alberta
Edmonton, Alberta, T6G 2G3
780-492-2699
anne.neufeld@ualberta.ca

BCCA Supervisor: Dr. Greg Hislop
Senior Epidemiologist, BCCA
Vancouver, BC V5Z 4E6
604-675-8060
ghislop@bccancer.bc.ca

You are invited to participate in a study on South Asian immigrant women's experiences of respect when they are in relationship with a health care provider. This study is going to take place at the British Columbia Cancer Agency in Vancouver and Surrey, British Columbia. This study will be at the outpatient clinic at the British Columbia Cancer Agency.

PURPOSE: In this study, we are interested in learning about South Asian immigrant women's experiences of respect when they are in a relationship with a health care provider.

PROCEDURE: If you are interested and willing to participate in this study, you will be involved in an interview. This interview will be audio-taped at a location convenient to you. It will last approximately sixty to ninety minutes. The interview will be done with your permission. A second interview may be necessary, but your permission will be asked again.

Savitri Singh will be calling you after you have received this letter to answer any questions regarding this study. If you feel that you want to be involved this study, feel free to give Savitri Singh a call at the number listed above.

VOLUNTARY PARTICIPATION:

BENEFITS: You may not get any direct benefits from this study. However other people may get benefits from what is learned in the study. You may look at your interview at any time. Some people learn things about themselves when they are in research studies.

RISKS: Your being in this study should not be harmful to you. We will respect your privacy at all times.

PRIVACY AND CONFIDENTIALITY: All the information will be kept confidential at all times. The tape recorded interviews, written materials, and audiotapes will be kept in locked files. This information will be destroyed after five years, or at any time, at your request.

FREEDOM TO WITHDRAW: You can withdraw from the study at any time without any consequences. You have the right to refuse any question in the interview. Your health care will not be affected by being in this study.

FUTURE USE OF DATA: We will present the findings from this study at health care providers' workshops for education. We will publish some of the findings. This information may also be used for secondary data analysis. Approval will be asked from the ethics committee first.

ADDITIONAL CONTACTS:

Dr. Marion Allen: Associate Dean, Faculty of Nursing, University of Alberta.
Phone Number: 780-492-6411.

Dr. Greg Hislop: Senior Epidemiologist, Cancer Control Research Program
Phone Number: 606-675-8060

Participant's initial: Researcher's initial:

(The participant gets one copy and the researcher keeps the copy with the participant's initials showing that they have received this information sheet)

Appendix C
Volunteer Recruitment Poster

A Brief Overview of the Study

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

You are invited to participate in a study on South Asian immigrant women's experiences of respect within health professional–client relationships at the British Columbia Cancer Agency outpatient clinics located in Vancouver and Surrey BC. The purpose of the study is to understand what South Asian immigrant women expect in the form of respect and how they perceive respect when they visit the outpatient clinic at the cancer agency. Please be assured that whatever you share in the interviews will be completely confidential. While each response is very important, findings will report overall patterns rather than individual responses.

We are looking for South Asian immigrant women who meet the following criteria:

- Those women who either had or have any type of cancer.
- Women who are currently going through cancer treatments or follow up visits.
- Are 18 years of age or older.
- Those women who immigrated to Canada at the age of twelve or older.
- Able and willing to share their experiences in Punjabi, Hindi or English.

If you interested or know of anyone who might be interested, please do not hesitate to contact us:

Savitri Singh RN MSN PhD (pc) student
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University of Alberta
ssingh@ualberta.ca
Vancouver telephone number 778-881-9130

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3rd Flr Clinical Sciences Bldg
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Edmonton, Alberta, T6G 2G3
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Appendix D

Patient Informed Consent

**South Asian Women's Perceptions of Respect within Health Professional/Client Relationships While Journeying through Cancer**

Principal Investigator: Savitri Singh RN MSN
PhD student, Faculty of Nursing
University of Alberta
Edmonton, Alberta
Vancouver telephone number: 778-881-9130

Supervisor: Anne Neufeld RN PhD
Professor, Faculty of Nursing
University of Alberta
Edmonton, Alberta
780-492-2699

| | Yes | No |
|---|---|---|
| Do you understand that you have been asked to be in a research study? | | |
| Have you read and received a copy of the attached information sheet? | | |
| Do you understand the benefits and risks involved in taking part in this research study? | | |
| Have you had an opportunity to ask questions and discuss the study? | | |
| Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care. | | |
| Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information? | | |

This study was explained to me by: _____

Date: _____

*I agree to take part in this study.*

Signature of Research Participant: _____

Printed Name: _____

Witness (if available): _____

Printed Name: _____

**I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.**

Researcher: _____

Printed Name: _____

* A copy of this consent form must be given to the subject.

## Appendix E

### Participant Observation Field Notes Guide

Participant observations will be aimed at describing the social setting of both clinical settings. Observations will focus on providing descriptions of health professionals' activities and daily routine procedures at the clinical settings. These descriptions will include observations of health professionals; health professional and the client; and the clinical setting. The purpose of the participant observation is to provide contextual data of the social setting and to observe how the agency's guidelines and policies manifest in the clinic. Observations will not include any data about the patient or their illnesses; the health care professional's performance when providing care; or any interactions or conversations within the relationship. This participant observation data will provide context to the participants' experiences.

The researcher will shadow a health professional from each discipline over a 2-week period at both sites. This observation will be done prior to data collection; however, the researcher has the option to go back after data collection to validate or confirm data. There will be no preset scheduling for observations; however the time and convenience will be negotiated with health professionals before initiating the observation. The health professional will ask the client's permission, and verbal consent will be granted before observations begin. Field notes of all observation sessions will be recorded in the form of journal notes immediately after to ensure reliability. These written field notes will be detailed to provide accuracy and clarity of daily activities, routines, and procedures. The written notes will be transcribed as part of data.

Appendix F

Sample Interview Trigger Questions

Study Title: South Asian Women's Perceptions of Respect within Health Professional/Client Relationships While Journeying through Cancer

Interview guide for South Asian immigrant women:

Being a South Asian woman who has cancer and has gone through the outpatient follow-up clinic at the cancer agency, perhaps you have some stories that you would like to share with us. Women in general may go through similar experiences while they visit the clinic, however I would like to hear your story as a South Asian woman immigrant woman, a woman who has visited the clinic for a cancer related treatment or a follow-up visit.

1. Please tell me about your visit/visits to the outpatient follow-up clinic at the British Columbia Cancer Agency.
2. Please tell me a story about a time or times when you experienced respect from a health professional during your visit to the out patient follow-up clinic.
    a. What are some other examples of experiences of respect during your visit to the clinic?
3. How did this experience make you feel? What if anything would you add?
4. From your experience, how would you describe situations, if any, where you have felt disrespected or experienced a lack of respect from a health professional at the clinic? Is there anything else you would like to add?
5. What advice would you give health professionals about enhancing or improving respect when they are caring for immigrant women at the clinic?
6. What is the meaning of respect to you personally as a woman? What influence does being a South Asian immigrant woman in Canada have on your views about respect?

# Appendix G

## Interview Field Notes Guide

Field notes of the interview setting will be aimed at describing the environment in which the interview takes place. The choice of the interview setting will be mutually agreed with the participant. Observations of the field setting will focus on the surroundings including a description of others who may be present or not, the participant's comfort level during the interview, and the length of the interview. Any nonverbal communication or gestures during the interview will be noted. These field notes will be written, audiotaped, and transcribed later to form part of the data. The researcher will record the field notes directly after the interview in order to ensure reliability.

# Appendix H

British Columbia Cancer Agency Mission Statements, Policies and Guidelines

www.bccancer.bc.ca

British Columbia Cancer Agency Strategic Plan

www.bccancer.bc.ca

# Appendix I

## List of Educational Material

This Educational Material is published by BC Cancer Agency

General Information

1. Brain tumour support group.
2. Canadian Cancer Society. Taking time: support for people living with cancer and people who care about them.
3. Home Hospice Program (Punjabi)
4. Listen with your heart
5. Patient & Family counselling services
6. Relaxation Support Groups in BC (Circle work)
7. Women living with recurrent or metastatic cancer
8. Relaxation program: information practice & support
9. Therapeutic touch for relaxation (British Columbia Cancer Agency)

Breast Cancer Clients

1. Breast cancer information packet generally given before the surgery
   - Olivotto, I., Gelmon, K., Kuusk, U., (2nd edition, 2001). The Intelligent Patient Guide to Breast Cancer. Murphy Woods: Vancouver, Canada.
   - Breast cancer companion guide calendar
   - Breast cancer navigation map
   - Canadian Cancer Society. Nutrition and breast cancer, what you should know.
   - After breast cancer treatment: what next? An awareness guide.
   - Abreast in the West. Winter 2006, volume 7, (1).
2. Canadian Cancer Society. Questions to ask about breast cancer, what you need to know.

Chemotherapy Clients

1. All about anaemia, fatigue, and cancer
2. Breast self-examination guide: The primary care & cancer
3. Canadian Cancer Society. Chemotherapy: A guide for people with cancer (available on the Web site in Punjabi) www. bccancer.bc.ca
4. Chemotherapy teaching session for new patients: How chemo works
5. Coping with taste change. Oncology nutrition
6. Fatigue: what is it
7. Follow-up program after breast cancer treatments by BC Cancer Agency

8. Food choices to help control nausea: Oncology nutrition
9. For the patient: managing nausea
10. From the FVC medical oncologist: information for our patients about after hours problems: acute and medical emergencies such as fever and nausea
11. Help line list of phone numbers for nursing, pharmacy, nutrition, counselling, etc.
12. Ovarian cancer: Knowledge is power. Information resource for women
13. Ovarian cancer Canada: Newly diagnosed (Punjabi)
14. Morphine oral solution (Punjabi)
15. Pain relief. Comfort measures
16. Suggestions for dealing with constipation
17. Symptom management on the Web site for chemotherapy clients www.bccancer.bc.ca/symptommanagement
18. Wigs and hair alternatives

Radiation Clients

1. Breast radiation therapy: information for patients.
2. Care of radiation therapy skin reactions
3. Diarrhoea and cramps
4. Food choices to help control nausea: nutrition services
5. Having a sitz bath at home: Instructions for patients
6. Loss of appetite
7. Mouth care
8. Nausea and vomiting
9. Patient satisfaction survey (Punjabi)
10. Radiation therapy for the whole pelvis: A female patient's guide
11. Radiation therapy for the whole abdomen and pelvis: For patients who have had ovarian cancer
12. Radiation therapy health irradiation
13. Radiation therapy: What to expect?
14. Saline compresses: Information for patients
15. Symptom management on the website for chemotherapy clients www.bccancer.bc.ca/symptommanagement
16. What do I need to know about radiation therapy to the breast?